

Managing malnutrition: appropriate interventions

Dementia is everybody's business

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violence and abuse

Chronic oedema explained

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Wound care service development over a five-year-period of national
change: role of partnership working and education delivery

Family and other unpaid carers supporting people with dementia

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Managing director

Alec O'Dare
alec@woundcarepeople.com

Editor-in-chief

Annette Bades
In-patient clinical lead,
Bury Hospice

Publisher/editor

Binkie Mais
binkie@jcn.co.uk

Sales manager

Sam Ciotkowski
sam@jcn.co.uk
01789 332162

© Wound Care People Limited 2022

Unit G, Wixford Park, George's Elm Lane,
Bidford on Avon, Alcester B50 4JS

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t: +44(0) 1789 582000

e: mail@jcn.co.uk

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Making a difference that matters



Welcome to our first issue of the *Journal of Community Nursing* for 2022. Over the coming year we will, as always, strive to support you and your practice and keep you updated on current topics. This issue highlights the vital role that all community-based professionals undertake on a daily basis and the importance of being an advocate for everyone that we make contact with. The support we can offer, both from ourselves and the wide range of services from other health and social care professionals, is invaluable and

will always make a difference to the lives of individuals we meet.

With an ageing population and more people living with dementia, inevitably comes an increased need for carers. As community nurses, we are in an ideal position to identify, support and value such unpaid carers, which the sixth part in our dementia series explores (pp. 47–51). Indeed, as Karen Harrison Denning rightly points out in her editorial (pp. 12–13), dementia is 'everybody's business'. I urge you to read this piece and think about challenging cases and concerns you have encountered and then take part in the survey mentioned, which seeks to capture and understand real-time issues when working with a person with dementia and/or their families. These will then inform a text providing advice and information from an Admiral Nurse.

This first issue of 2022 is packed full of clinical articles relevant to your day-to-day practice. For example, with more people choosing to die at home, it is vital that clinicians have the training and confidence to help provide a dignified and comfortable death. The article on using syringe drivers at the end of life looks at the conditions they aim to treat, detailing the author's own experience of caring for a patient at life's end and developing a rapport with her family at this time (pp. 35–39). Safeguarding is another area that is 'everyone's concern', which community nurses need to know how to recognise and report. Darren Butler, named nurse adult safeguarding, Cambridgeshire and Peterborough NHS Foundation Trust, provides a detailed account of the different types of abuse and how to document your concerns (pp. 60–65).

As always, I hope you enjoy reading the journal. If you have any ideas for articles, please get in touch, as it is always great to hear from our readers. And finally, don't forget to check when the JCN exhibition and study days are coming to your area — www.jcn.co.uk/events/series/roadshow-study-day.

Annette Bades, editor-in-chief, JCN

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Sue Boran, *director of nursing programmes, Queen's Nursing Institute*

Beverley Brathwaite, *senior lecturer adult nursing, University of Hertfordshire*

Sara Burr, *community dermatology nurse specialist, Norfolk Community Health and Care NHS Trust*

Rachel Drago, *advanced nurse practitioner, The Mount Surgery, Pontypool; Queen's Nurse*

Sharon Eustice, *consultant nurse, Cornwall Foundation Trust*

Stefan Franks, *school nurse, West Sussex*

Gail Goddard, *mobile district nurse team manager, Hounslow and Richmond Community Healthcare; associate lecturer, Bucks New University*

Sharon Holroyd, *retired lead continence nurse*

Sally Lee, *post-doctoral research fellow at Bournemouth University*

Melanie Lumbers, *freelance tissue viability nurse*

Debbie Myers, *head of clinical and professional development, Quality and Professional Development Team, Leeds Community Healthcare NHS Trust*

Shirley Pickstock, *advanced clinical practitioner, Shrewsbury and Telford NHS Trust*

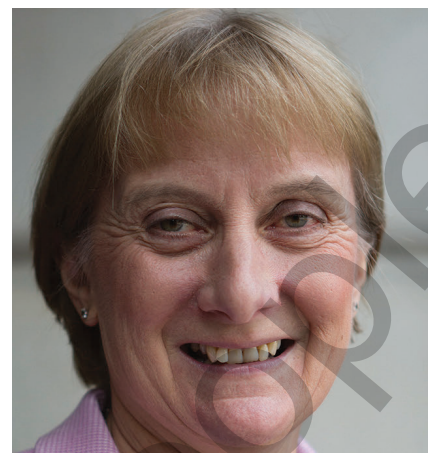
Georgina Ritchie, *deputy director of education, Accelerate*

Hattie Taylor, *district nurse lead (Purbeck), Dorset Healthcare University NHS Foundation Trust; Queen's Nurse*

Jane Todhunter, *vascular nurse practitioner, North Cumbria University Hospitals*

Anne Williams, *Lecturer, University of the West of Scotland; lymphoedema nurse consultant, Esklymphology*

Janelle Yorke, *senior lecturer, School of Nursing, Midwifery and Social Work, University of Manchester*



I am a district nurse, nurse teacher in practice, associate lecturer and Queen's Nurse who believes that excellent community nursing is vital and that community nurses should be more visible. Care should be available to everyone who wishes to remain at home. I have an interest in dementia, end-of-life care and teaching in practice to support newly qualified nurses. I am very pleased to be a part of the JCN editorial board, an accessible journal for all community nurses to inform their practice and strive for excellent care.
Gail Goddard

I am a district nurse, nurse teacher and Queen's Nurse with a passion for excellent community nursing education and practice. I am also an advocate for care being close to people's homes and for supporting people to self-care and regain independence where possible. I also have an interest in nurse prescribing, dementia, frailty, loneliness and social isolation. I am delighted to be a part of the JCN editorial board, a journal for all community nurses to access for the very latest and best evidence to inform their practice.
Sue Boran



I am a freelance tissue viability nurse (TVN) and health visitor. My true passions are in pressure area care and moisture-associated skin damage. I sit as a registrant panel member on the NMC Fitness to Practice Hearings, and work with the Institute of Health Visiting (IHV), where I have recently supported the development of a training package on domestic violence and abuse (DVA). I am delighted to be part of the JCN editorial board, where current best practice can be discussed.
Melanie Lumbers

I've been working in district and community nursing for 20 years. My particular passion is for continuity of care in community nursing, which encourages healthy behaviour, builds trusting relationships, can reduce healing times, and makes people feel more positive about their healthcare experience. We have a responsibility to prepare for the future by continuing to develop leadership and clinical skills. The JCN is a great resource for support, education and to share best practice.
Hattie Taylor

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Imogen Watson, dietitian, medical and scientific affairs manager, Abbott

Malnutrition (or under-nutrition) is a state of nutrition in which a deficiency or excess (or imbalance) of energy, protein and other nutrients causes measurable adverse effects on tissue/body form (body shape, size and composition) and function and clinical outcome (British Association for Parenteral and Enteral Nutrition [BAPEN], 2018).

Malnutrition affects at least three million people in the UK, with 93% of these living in the community (BAPEN, 2018). It has an estimated cost of £19.6 billion in England, and can lead to adverse effects if unidentified and untreated, such as increased infections, wounds, complications and mortality, leading to greater healthcare use through increased hospital admissions, longer hospital stays, more GP visits and increased prescription costs (Stratton et al, 2018). The large costs of this condition are mainly due to poorer patient outcomes leading to greater healthcare use by malnourished patients when untreated. The high costs are not because of expenditure on strategies to manage malnutrition, estimated as less than 2.5% of the overall cost of malnutrition (Stratton et al, 2018).

Conversely, managing malnutrition can result in improvements in patients' physical function, such as strength, quality of life and clinical outcomes, and reductions in healthcare use (such

Managing malnutrition: appropriate interventions

'Good nutritional care is a vital part of patient management and intervention can include the provision of nutritious food, dietary counselling, oral nutritional supplements (ONS), tube feeding and parenteral nutrition.'

as hospital stays and admissions) (Stratton et al, 2018).

Identifying and managing malnutrition can therefore improve lives and save money (Stratton et al, 2018). The first step in nutritional risk identification is nutritional screening. This is recommended by the National Institute for Health and Care Excellence (NICE, 2006) and BAPEN (2021). NICE and BAPEN recommend that all patients should be screened at first contact (both in- and outpatients), with regular screening thereafter being implemented, as clinical condition and nutritional status can change. Post screening, nutritional intervention and monitoring should be put in place as indicated for the individual patient (BAPEN, 2021).

There are many tools available to support screening, including 'MUST' (Malnutrition Universal Screening Tool; BAPEN, 2020) and R-MAPP (Remote - Malnutrition APP) (Krznicaric and Bender, 2020), which incorporates 'MUST' and the SARC-F tool, a simple and easy five-item questionnaire (strength, assistance with walking, rise from a chair, climb stairs and falls) for screening sarcopenia in older adults. In the author's clinical opinion, as key

frontline healthcare professionals, community nurses are well placed to screen patients for nutritional risk.

The next step in managing malnutrition is intervention when indicated through screening and assessment. Good nutritional care is a vital part of patient management and intervention can include:

- ▶ Provision of nutritious food
- ▶ Dietary counselling
- ▶ Oral nutritional supplements (ONS)
- ▶ Tube feeding
- ▶ Parenteral nutrition (Medical Nutrition International Industry [MNI], 2012).

ONS are an effective and non-invasive solution to manage malnutrition in patients who are able to consume some normal food, but not enough to meet nutritional requirements (MNI, 2012).

ONS are widely used within the acute and community health settings. They come in a variety of preparations, including liquids, semi-solids or powders, providing a range of macro and micronutrients. They are commercially produced and prescribed to improve nutritional status, treat malnutrition, and have been proven to have good outcomes when used appropriately (Rabess, 2021). Evidence from the highest quality

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- ▶ RMAPP app: www.rmapptool.com/en
- ▶ 'MUST': www.bapen.org.uk/pdfs/must/must_full.pdf

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‡ The market leader for juice style ONS. Based on IQVIA retail sales analysis data, units, MAT July 2021, across all juice style oral nutritional supplement products.

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studies (systematic reviews) suggest that ONS can (Rabess, 2021):

- ▶ Reduce mortality rates
- ▶ Increase overall energy intake
- ▶ Support weight gain in a variety of clinical conditions
- ▶ Decrease complications and length of hospital stay.

However, to maximise both clinical and cost-effectiveness, it is important to achieve good compliance (Hubbard et al, 2012). Compliance to ONS can vary widely, from 37–100% (Hubbard et al, 2012), and can be affected by many factors, including taste, variety and palatability (Nieuwenhuizen et al, 2010). Personal factors also need to be considered, such as dietary preferences. For example, if a patient dislikes milk or milky drinks, a juice-style ONS is likely to be better accepted. *Figure 1* provides some factors and questions to consider before initiating a patient on an ONS.

CONCLUSION

In summary, identifying patients with, or at risk of malnutrition, and intervening with nutritional support as required can lead to positive clinical and economic outcomes. Nutritional support can include a variety of management strategies, including ONS when indicated.

ONS have been shown to be clinically effective in the management of disease-related malnutrition. However, to maximise both clinical and cost-effectiveness, it is important to achieve good compliance. Compliance can be affected by a range of parameters, including taste, variety and palatability. Personal factors and preferences also need to be considered, such as offering a juice-style ONS if a patient dislikes milkshake-style ONS. Such strategies can support compliance with ONS, helping to achieve desired outcomes. **JCN**

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- ▶ Does your patient suffer with taste fatigue or taste changes? Do they dislike milkshake-style drinks? Consider a juice-style ONS
- ▶ Do they have high protein needs? For example, chronic obstructive pulmonary disease (COPD), wounds, postoperative patients, some types of cancer, older people with frailty, patients who have been in ICU, patients with sarcopenia. Consider a high protein ONS
- ▶ Is there a history of gastrointestinal (GI) symptoms of malabsorption or maldigestion, such as diarrhoea, steatorrhoea, nausea/vomiting/reflux? Consider a peptide-based ONS
- ▶ Does the patient have difficulties with food preparation and/or poor hand dexterity? If so, a powdered ONS is likely to be inappropriate and a ready-to-drink ONS should be considered
- ▶ Could larger volume supplements be a challenge for your patient? A compact style (125ml), ready-to-drink ONS may be better tolerated. Only use a powdered style ONS if you have assessed the ability of the patient to make it up
- ▶ What is the patient's usual bowel habit? Does the patient have a history of constipation and low dietary fibre intake? Would they benefit from an ONS with added fibre?
- ▶ Does the patient have dysphagia? Ensure that the patient has an appropriate modified consistency directed by a speech and language therapist.

Figure 1.
Factors to consider when introducing an ONS.

'... identifying patients with, or at risk of malnutrition, and intervening with nutritional support as required can lead to positive clinical and economic outcomes.'

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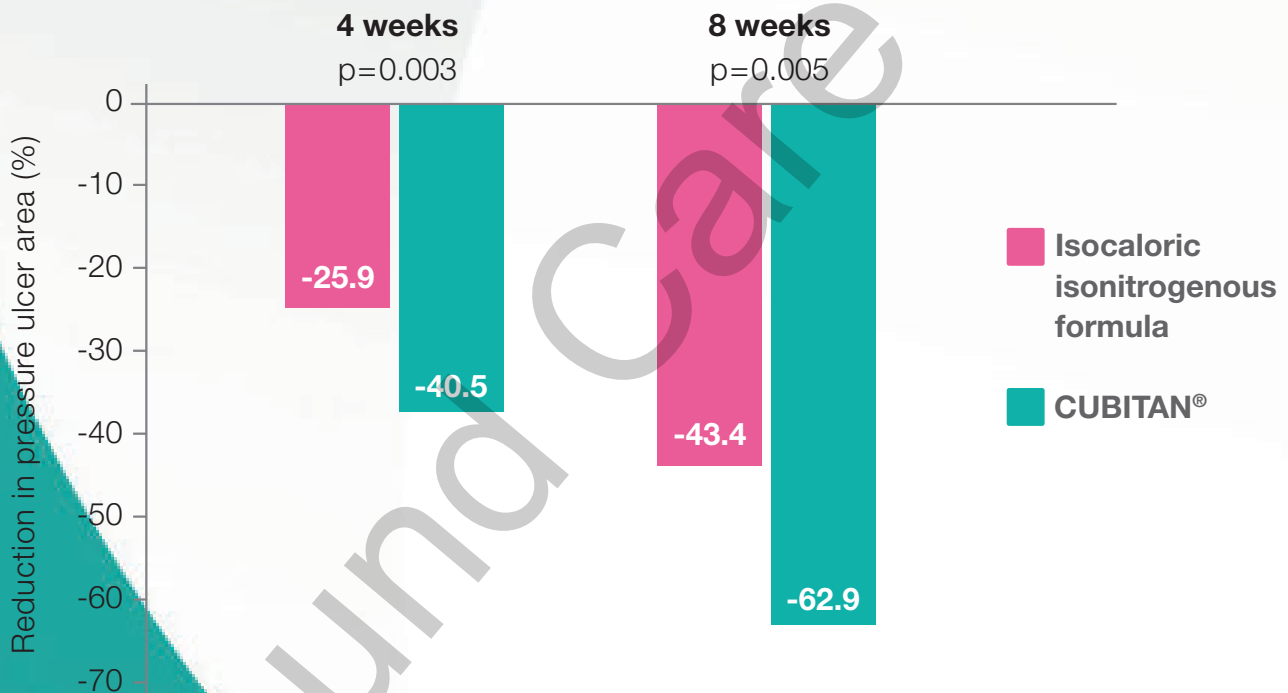
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Karen Harrison Denning, head of research and publications, Dementia UK (Admiral Nursing) and professor of dementia, De Montfort University, Leicester

Dementia is everybody's business

There are estimated to be 900,000 people with dementia in the UK and indications are that this will increase to one million people by 2025 and two million by 2051 (Wittenberg et al, 2019). While dementia is associated with old age, there are approximately 42,500 people under the age of 65 years old diagnosed with young onset dementia (Sandilyan and Denning, 2019). Due to the progressive nature and neurodegeneration of dementia, it is now the leading cause of death in England and Wales, accounting for 12.5% of all deaths registered in 2019 (Office for National Statistics [ONS], 2020).

The majority of people diagnosed with dementia live in a community setting, whether that is in their own home, sheltered accommodation, hospice or a care home; indeed, there are few health and social care services where people with dementia are not to be found, and, as such, dementia is everybody's business. It is likely that generalist clinicians in primary care, such as community nurses, GPs, pharmacists and occupational therapists, will be a person's first port of call when they report that 'something' is not right, or they are facing difficulties. Similarly, such clinicians may also observe early changes in their existing

patients that indicate a possibility of dementia during regular clinical activities. As such, they may need to take appropriate action in initiating the referral process for a memory assessment (Harrison Denning and Aldridge, 2021).

Once the diagnosis of dementia is made, this does not mean that the person will automatically come under the direct care and supervision of specialist dementia services from there on. Specialist dementia services, frequently situated in secondary mental health services, are often only available to those affected by dementia who have complex needs, such as comorbid mental health conditions, behavioural problems, or other complexities, whether this is through continued monitoring from a memory assessment service or a dementia intervention team.

However, there are a growing number of Admiral Nurses across the UK, specialists in dementia care, who support families affected by dementia in a range of settings and care contexts. Admiral Nurses offer a case management approach to help families understand dementia and its effects, and help them to develop the confidence to manage and navigate their future with dementia. Another significant element of this specialist role is to support generalist clinicians to work with families affected by dementia on their own caseloads and in their everyday practice, through supervision, mentorship and educational interventions.

One of the standard educational resources used across health and social care is that of educational texts, be these in a standard book or journal format or an online resource. Such resources aim to provide information and guidance to generalist practitioners on aspects of dementia. Indeed, the author has produced one herself (Harrison Denning, 2019), but these resources often follow a standard format of the author telling the reader what they think they need to know. They are often formulaic, introducing dementia as a disease, risk factors, detailing its biochemistry, its sub-types, early signs of the condition, behaviours that challenge, carer needs, etc. However, the author of this piece and colleagues wish to 'flip' this standard approach by working on a format to a new text that starts by asking generalist clinicians:

What do you want to know?

What is an issue for you when working with a person with dementia and/or their families?

Generalist clinicians often have a case (or several) that presents them with various concerns, issues and dilemmas. Thus, the author and colleagues would like to invite JCN readers to tell them through anonymised cases, their issues and concerns to which they will respond by situating specialist advice within real cases and issues. A type of training needs analysis will be undertaken that will drive the content of this new book by eliciting a set of themes of learning needs from the questions posed to them.

Training needs analyses (TNA) are used to establish the continuing professional development (CPD) needs of a healthcare workforce and seek to identify the gap between the knowledge and skills of an individual (Barbazette, 2006). When planning a TNA, Brown (2002) urges us to first ask several questions, such as, what is the nature of the problem to be addressed by the training? How have training needs been identified and with what results? To meet these requirements, the author and colleagues' call will be as wide as possible through professional journals (such as this one), clinical networks, professional social media channels, and snowballing (word of mouth from one professional to another).

Once themes have been identified, individual clinicians will be asked to tell their case or issue. Any case used within the book

will be anonymised and used for illustration purposes and to guide specific advice and information from an Admiral Nurse.

We invite you to complete our online survey tool by visiting: www.smartsurvey.co.uk/s/working_with_dementia/. Alternatively, if you want to discuss your involvement further, please contact: karen.harrison-dening@dementiauk.org **JCN**

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Dementia UK's free Helpline is staffed by specialist Admiral Nurses who can provide support, information and advice about any aspect of dementia. The Helpline is available to anyone who would like to speak to an Admiral Nurse, including health and social care professionals. Call 0800 888 6678 (Monday–Friday 9am–9pm, Saturday and Sunday 9am–5pm, every day except 25th December), or email helpline@dementiauk.org.





Sonya Carassik Ratty, interim marketing manager, Bladder and Bowel UK

Supporting bladder and bowel services to evolve and thrive

Now more than ever, those with an interest or specialism in continence care need to be able to access professional development, as well as share knowledge and experiences with colleagues. Covid-19 has rapidly altered service provision and specialist professionals working across different geographical areas have not yet had sufficient opportunity to come together in person and process what these changes mean for their practice and patients. This upheaval has, of course, affected everyone whose work touches on bladder and bowel issues.

Ongoing specialist education has taken a hit. This is one of the reasons that Bladder & Bowel UK's symposium in Bolton on 9 March 2022 represents such an exciting and valuable opportunity: three concurrent streams — covering paediatric and adult bladder and bowel care — with a varied programme, including expert speakers. At a time when healthcare professionals are under more pressure than ever, the symposium programmes have been designed to meet diverse educational needs within this specialist field of practice.

Given the current state of affairs, it is no wonder that professionals working in the field of bladder and bowel care are enthusiastic about returning to in-person events. We await results from the EPICCC-19 study from the University of the West of England, University of Bristol and the

National Institute for Health Research Applied Research Collaboration West, which is assessing the impact that the pandemic has had on community continence care services for adults and children. It is anticipated to show that widespread service redeployment, resulting in lengthy waiting times, alongside reduced access to specialist education, have taken a major toll on the scale and reach of continence services — as well as on the morale of the professionals delivering them.

This continues a trend of bladder and bowel services falling into that unenviable category of 'Cinderella services', with services continuing to lack investment, recognition and succession planning, with many undergraduate education programmes still barely touching on this subject. This is despite the significant day-to-day negative impact of continence issues on patients' lives, and those of their carers. The enduring taboo of incontinence has a knock-on effect on recruitment into this specialist area. For those with bladder and bowel difficulties, the stigma and embarrassment affects their ability to approach their healthcare professional, as well as subsequent engagement and compliance with treatment regimens (Hägglund and Wadensten, 2007). The pandemic has likely exacerbated the barriers to access, with continence services one of the first areas to be targeted for redeployment. What is more, over the past two years, access to the physical examination element of essential patient assessments by continence specialists, has been restricted. While there are undoubtedly some opportunities presented by remote assessments, the complexities are extensive.

Similarly, the accelerated shift to remote education has its benefits, but the continence field finds itself poorer after the scarcity of face-to-face

education. Given that bladder and bowel care remains underfunded and insufficiently recognised (Eustice, 2013), the relationships between professionals in the field are integral to its progression, development, functioning and sustainability into the future. These relationships need forums to facilitate personal, professional and service development, so that patients continue to receive quality care based on the best and most up-to-date evidence.

Bladder & Bowel UK's symposium will be the organisation's first in-person event in two years, providing delegates with some of that much-missed opportunity to update skills and knowledge as well as to meet friends and colleagues from other services across the country. Evidence of attendance is provided for seven hours of continuing professional development and NMC revalidation.

This exciting event will allow continence professionals to reflect on the past two extraordinary years, and to maintain professional development and promote excellence in the specialism, ensuring that bladder and bowel services continue to evolve and thrive in the future. **JCN**

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ZIPZOC[◇]

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FP10 Drug Tarrif	PIP Code
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ZIPZOC (zinc impregnated medicated stocking) **Abbreviated prescribing information.** Refer to summary of product characteristics before prescribing.
Composition: A sterile rayon stocking impregnated with an ointment containing 20% Zinc Oxide. Each stocking (80cm x 7cm) contains about 41.5g of ointment. **Therapeutic indications:** Aid to the treatment of chronic leg ulcers and other associated skin conditions. Where chronic venous insufficiency exists, the medicated stocking can be used as a primary contact layer under compression bandaging or hosiery. **Method of Administration:** Because ZIPZOC is preservative free, it must be changed no less frequently than weekly. For topical application, ZIPZOC should be applied to cover the lower leg from the base of the toes to below the knee. All folds should be smoothed out. To protect clothing, a suitable outer bandage should be worn. If chronic venous insufficiency exists, ZIPZOC may be used as a primary contact layer under compression therapy and may be left in situ for one week, before re-application.
Contra-indications: Arterial leg ulcers. Known hypersensitivity to zinc oxide or the excipients in the ointment. **Special Warnings and Special Precautions:** None known. **Interactions:** None known. **Pregnancy and Lactation:** There is no evidence to suggest ZIPZOC should not be used during pregnancy. **Undesirable Effects:** The skin of leg ulcer patients is easily sensitised to some topical medications. ZIPZOC contains no preservatives thereby reducing the risk of skin reactions. Reported reactions include, rash, erythema, itching and maceration of the wound edge. If the outer bandage is inappropriate or the medicated stocking is not changed with sufficient frequency it can cause the stocking to dry out. **Excipients:** Liquid Paraffin Ph. Eur. White Soft Paraffin BP. **Incompatibilities:** None reported. **Shelf Life:** 3 years. **Storage:** At or below 30°C. Keep all medicines out of the reach of children. **Packaging:** Polyethylene aluminium foil laminated pouches, each pouch containing a single medicated stocking. The outer carton will contain either 4 or 10 pouches. **Legal Category:** P **Market authorization number:** PL44616/0002 **Date of first authorisation/renewal of the authorisation:** 01 October 2006 **Date of revision of text:** 26 October 2018 **Trade Mark of Evolan Pharma AB** **Date of preparation:** October 2018



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- CaHMB. Calcium β-hydroxy β-methylbutyrate
 Job code: UK-ENSC-2100032 Date of preparation: December 2021
 For Healthcare Professionals only

*Ensure Plus Advance is an oral nutritional supplement for frail elderly people (>65 years of age, with a BMI ≤23 kg/m²), where clinical assessment and nutritional screening show the individual to be at risk of undernutrition. †Strength & functionality were measured by handgrip strength in a post hoc analysis of over 600 malnourished people with heart or lung diseases, age 65 or older. Ensure Plus Advance was consumed twice daily for 90 days. **Ensure Plus juice contains milk protein.

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NUTRITION PREHABILITATION IN CANCER CARE: HELPING PATIENTS TO ACHIEVE THE BEST OUTCOMES FROM TREATMENT



Imogen Watson RD, Medical & Scientific Affairs Manager, Abbott

Good nutrition is a crucial component of cancer management, helping patients to better cope with their illness and the toll of treatment.¹ Never has this been in sharper focus than during the COVID-19 pandemic, where many patients have received delayed diagnosis and prolonged treatment intervals.²

THE PREHABILITATION JOURNEY TO PHYSICAL HEALTH

Malnutrition is often one of the first physical symptoms of cancer, with 15-40% of cancer patients reporting weight loss at diagnosis.¹ These incidences increase rapidly to >80% during treatment, compounded by disease progression and cancer therapies, leading to cachexia.¹ Muscle protein depletion is a hallmark of cancer cachexia, severely impinging on quality of life, physical function and treatment tolerance.³

The concept of prehabilitation – including nutrition, physical activity and mental wellbeing – has been gaining support in oncology, where it has been shown to significantly improve long-term physical outcomes.⁴ Nutritional intervention should start at the beginning of the patient's cancer journey and should extend into the rehabilitative and even remission periods.^{3,5}

THE VITAL ROLE OF CANCER CLINICAL NURSE SPECIALISTS

Oncology Clinical Nurse Specialists (CNS) are well placed to support prehabilitation and conduct early screening for malnutrition and muscle loss. There are a number of tools available including the Remote Malnutrition App (R-MAPP), a simple screening method developed by nutrition experts using validated tools [Malnutrition Universal Screening Tool ('MUST') and SARC-F].⁶⁻⁸ Abbott has adapted R-MAPP as a digital tool to increase access by healthcare professionals.

MANAGING MALNUTRITION AND MUSCLE LOSS IN PEOPLE WITH CANCER – MAIN CONSIDERATIONS

Once nutritional status is confirmed, intervention aims to maintain muscle and physical performance, reduce the risk of further weight loss or interruptions of scheduled anti-cancer treatments, and improve quality of life. In patients with a normal functioning gastrointestinal system, the ideal way to maintain or increase energy and protein intake is with normal food intake, with the following considerations:^{3,9}

Energy	25-30 kcal/kg body weight/day
Protein	>1 g/kg body weight/day, up to 1.5 g/kg body weight/day
Muscle building	Leucine & its metabolite β -hydroxy β -methylbutyrate (HMB), a potent stimulator of muscle protein synthesis ⁹
Micronutrients	E.g. vitamin D, which is often deficient in people with cancer ⁹

Fig 1: What does the daily protein intake look like for a patient with cancer weighing 60 kg (up to 90 grams of protein/day)

Food	Approximate protein (g) ¹⁰
1 pint full fat milk	20
45 g cornflakes	3
x2 pieces wholemeal bread & butter, 50 g cheddar cheese	20
100 g grilled chicken breast & vegetables	36
Low fat fruit yoghurt (150 g pot)	6

NOT ALWAYS AS SIMPLE AS JUST EATING THE RIGHT FOODS

Cancer patients often suffer from reduced appetite, altered food preferences, taste changes, dysphagia, nausea, mucositis and pain, all of which may affect their ability and desire to eat. If a patient is malnourished, consider oral nutritional supplements (ONS). ONS are available in different formulations to address existing nutritional deficiencies. Compliance is key to ensure patients receive optimal benefits.

WORKING TOGETHER TO PROVIDE OPTIMAL NUTRITIONAL SUPPORT FOR ALL CANCER PATIENTS

Malnutrition is common in people with cancer. Oncology CNS are well placed to identify malnutrition and loss of muscle mass early on.

At Abbott, we provide a broad range of ONS to support malnourished patients at every stage of their journey. If you feel your patients need nutritional support, speak to your oncology specialist dietitian or contact the patient's GP.

USEFUL RESOURCES

- Remote Malnutrition App (R-MAPP): https://rmapptool.com/en/form?utm_source=advertorial+&utm_medium=journal&utm_campaign=advertorialjournal&utm_id=advertorial_journal
- Abbott Nutrition Health Institute (ANHI): <https://anhi.org.uk>

Please also look out for additional resources from Abbott in the coming months.

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Job code: UK-ENSC-2100032 Date of preparation: December 2021



Andy Holman, business development manager, medi UK

Although it may not attract as much attention as other medical areas, the pandemic has had a huge impact on wound care services with many traditional routes of practice compromised during life in lockdown. But, while this continues to add pressure on the nursing community, it also offers an opportunity to retain the recent step change in innovation to tackle backlogs and build back stronger.

Part of this will rely on the integration of new technologies and different, more agile ways of working to drive efficiencies and better patient outcomes. Until recently, for example, it might have been assumed that compression hosiery, widely used to treat and manage venous disease, left little scope for improvement. But, thanks to a recent period of innovation, this is no longer the case.

Even before the pandemic, the onus on rethinking chronic wound care treatment to refocus standards and drive better patient outcomes was high on the NHS agenda.

Over the years, wound care has continued to exert heavy financial and clinical tolls. Each year, the NHS manages an estimated 2.2 million patients with wounds, the equivalent of about 4.5% of UK adults (Guest et al, 2015). The cost to the NHS of managing these wounds and associated comorbidities — which can involve millions of practice nurses, community nurses, GPs and hospital

Reimagining compression hosiery for venous disease

staff — is estimated at £5.3 billion per year (www.eoecph.nhs.uk/wound-care.htm). This figure is 'comparable with that of managing obesity' (Greener, 2019; Schofield, 2021).

But, it isn't just about the economic burden — chronic wounds can have a huge toll on patients. It is the author's understanding that, besides from the pain and emotional distress, they can drastically impact on quality of life causing reduced mobility, unpleasant odour, sleep disturbances, social isolation and the inability to perform everyday duties.

In the main, the author has found that the issue has appeared to be one of suboptimal care. Inherently, early diagnosis and treatment is imperative to preventing chronic wound complications and improving healing rates for patients.

However, standards of wound care across the country can vary considerably, with studies pointing towards an underuse of evidence-based practices and overuse of ineffective interventions, not to mention a widespread shortage of specialist staff (Guest et al, 2015). As a result, wound healing rates have been found to be only 43% after one year (Guest et al, 2015).

In England, the National Wound Care Strategy Programme (NWCSP, www.nationalwoundcarestrategy.net/) seeks to address this by achieving a consistently high standard in the prevention, assessment and treatment of people with chronic wounds. However, this holistic, nationwide programme did not, of course, account for a worldwide pandemic.

A COMPOUNDED ISSUE

As busy community nurses know only too well, the pandemic has

compounded existing issues in wound healing rates and practices.

During this time, many specialist wound care services have had to temporarily shut or drastically reduce their services as staff are redeployed to other areas. For many wound care patients, many elderly, this has meant that they have not seen their specialist nurse or even GP unless in the case of an emergency.

Alongside this has been a widespread failure to seek treatment, most commonly because of patients not wanting to put pressure on the NHS or being concerned about catching Covid-19.

Indicative of this, initial prescription cost analysis data suggests a significant dip in the prescription of compression garments used to manage vascular conditions and chronic oedema during this period (www.nhsbsa.nhs.uk) — suggesting that patients have continued to use old garments which, most likely, would not have been fit for purpose.

Needless to say, while it's still too early to quantify exacting figures, anecdotally many nurses have warned of the impact of unmanaged chronic wounds in terms of numbers and the severity of wounds now in the community.

A POSITIVE LEGACY

However, there are some positives to report too. Necessity being the mother of invention, the past 18 months have prompted a notable pivot to innovation.

This has been seen by more consultations taking place online or by telephone — a move which might have previously been inconceivable — which continues to work well to this day.

Another trend has been the marked shift towards 'supported self-care', whereby patients and their families, in the absence of home visits, have become increasingly responsible for managing their or their family member's recovery. The positive impact of this continues to be seen, as many patients become more empowered in taking control of their own care, if appropriate, thus alleviating day-to-day nursing requirements (GSK and IPSOS, 2020).

In the author's opinion, this has sharpened focus on the importance of breaking down the barriers of bureaucracy and creating a more fluid, open working environment — one which nurtures new thinking and embraces innovation to achieve better patient outcomes. Indeed, it is this step change in innovation which should play a central role in addressing many of the new, pandemic-induced challenges now facing wound care services.

NEW GROUND IN COMPRESSION HOSIERY

Take, for example, the compression stocking category. Although almost everyone with a chronic wound will need a compression therapy management plan to help it to heal and stay healed, it is perhaps surprising that compression hosiery has seen limited innovation. To date, it is the understanding of medi UK — having operated globally for many years — that solutions have typically comprised a standard one-piece design in the same type of compressive stocking material, and remained largely unchanged.

However, this is changing with the arrival of the next generation of compression stocking.

A product of research and innovation, duomed® soft 2easy® (medi UK; *Figure 1*), is a two-piece compression hosiery system which has been purposefully designed to make it easier for patients to apply and remove their compression garment. This product is the result of a collaboration between Dr Robert Lister, a dermatologist at Wrexham Maelor Hospital, and medi UK.

With over two decades in the medical field, Dr Lister had recognised a worrying trend among patients, i.e. many elderly failing to wear the compression garments required to manage vascular conditions and chronic oedema. This was usually because they found the compressive nature of the garments and restrictive one-piece design difficult to put on and take off, especially in the case of those with limited dexterity. For many patients, the result of failing to use these garments was that their underlying conditions escalated — for some, even leading to a foul-smelling open wound — resulting in chronic pain and a huge impact on their quality of life.

In response, Dr Lister decided to take matters into his own hands and invented a two-piece compression stocking system — anklet and separate calf sleeve — which can be more easily manoeuvred over a patient's foot, even for those with limited abilities.

Four years later, the product has been developed and fast-tracked to market due to the manufacturing capabilities of medi UK, becoming available on NHS prescription 1 December, 2021.

As busy community nurses continue to tackle the Covid-19 backlog, it is hoped that this solution will help to ensure a more effective treatment for unmanaged wounds, speed up healing times, and maintain healing levels.

In the long term, it is the author's hope that early intervention with a compression hosiery garment that is easy to use so the patient commits to wearing it, will mean that the risk of developing a chronic wound and the associated impact on patient quality of life are reduced.

A NEW PATHWAY

As community nurses may agree, if the NHS is to realise the aims set out in the NWCSP, while addressing the challenges afforded by the Covid-19 backlog, it cannot stand still.

Rather like the step change in



Figure 1. duomed® soft 2easy® (medi UK).

innovation encountered during the pandemic peak, achieving the wound care mandate must rely on new thinking and innovation to establish more agile practices and greater efficiencies. By taking advantage of this opportunity in compression hosiery, nurses can establish a new pathway to early intervention, more consistent care and, most importantly, better patient outcomes. **JCN**

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FOR MORE INFORMATION...

... on medi UK, please visit: www.mediuk.co.uk

Working with a community for change: tackling domestic violence and abuse

Domestic violence and abuse (DVA) is a real issue for many people. It is also sadly in places in our communities and life spaces. During the pandemic, the evidence seems to say things have got worse (<https://commonslibrary.parliament.uk/domestic-abuse-and-covid-19-a-year-into-the-pandemic/>). Indeed, victims were suddenly trapped at home with their abuser, with no options of respite or relief (Chambers et al, 2021).

The police nationally reported receiving a call every 30 seconds about domestic violence and abuse during the first seven weeks of lockdown (McDonald, 2020). The National Domestic Abuse helpline reported a 49% increase of calls and Refuge (UK's largest domestic abuse charity) reported a 120% increase in calls on 6th April 2021 compared to the previous day (Refuge, 2021).

The authors work in a health and care model called a local care partnership (LCP). The LCP is a partnership way of joined-up work to deliver local care for local people; working in and with communities. It brings together community nurses and teams, GP services, third sector

'You cannot know what a person or a community needs, until you first know what it has.'

John McKnight, a founder of the asset-based community development approach

organisations, social care, elected members, such as local councillors, and others in a new way of working and learning together. It seeks a new paradigm of working beyond silos and systems to co-create good health and wellbeing outcomes with people where they are.

There are 15 LCPs in Leeds covering every part of the city. They recognise the diversity of the city and seek to be tailored to local needs and the features and strengths of the particular community in which they work.

Seacroft is an inner east city suburb and has significant challenges in terms of material deprivation. The Seacroft LCP works in and with the local communities. The partnership includes: third

sector organisations, elected councillors, primary care, other NHS healthcare services (i.e. community healthcare, pharmacists, and allied healthcare professionals), mental health services, children's centres, housing and adult social care.

Seacroft LCP recognised the significant need to respond to DVA (particularly as a result of Covid-19), and aimed to do three fundamental things, namely:


- ▶ Listen to local people
- ▶ Bring the partner services together in a cohesive plan
- ▶ Build with local people in the community, actions and initiatives that could support those undergoing DVA.

Listening to the local community

The authors met with community members who attended the third sector organisation, LS14 Trust (see box), and told them about the DVA priority. This resulted in a safe space for families to chat about their stories and what areas we should be looking to improve in regards to the DVA work. A community member told a story about her being a child going through DVA via her family.



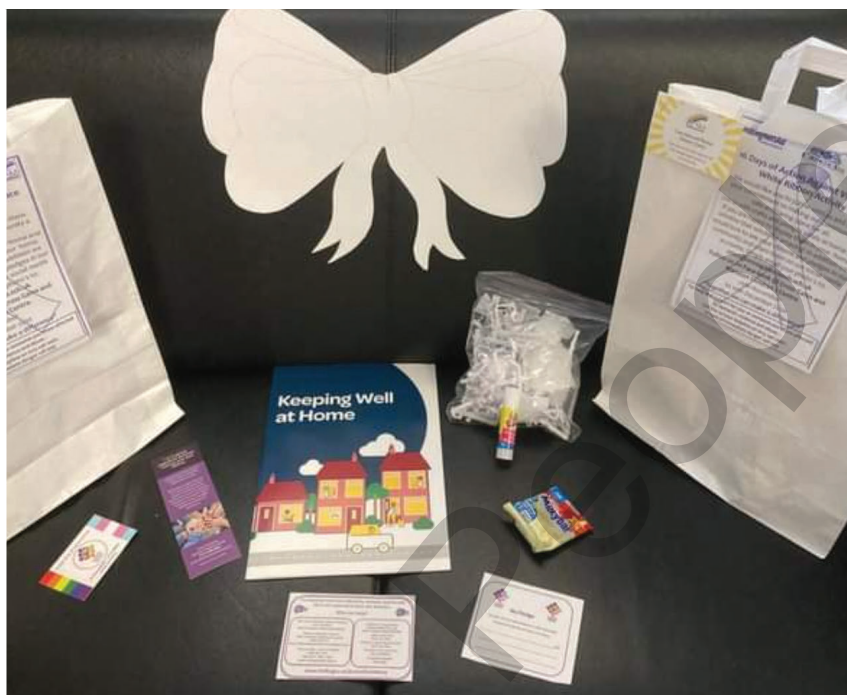
From left to right: Rachel Ainscough, senior development manager; Ana Mesarovic, project support officer, both at Leeds Local Care Partnership Development Programme; John Walsh, OD lead/Freedom to Speak Up Guardian, Leeds Community Healthcare NHS Trust/Leeds GP Confederation

 Cross Gates and Manston Children's Centre is at Cross Gates and Manston Children's Centre.

1 h · Leeds · 🌐

Wow Wow Wow ! 💜💜💜

Would you believe it but we are already one week in to the '16 Days of Action' campaign!!! It's 🌟 A... See more



This led to further discussions and listening with members of the community around DVA.

Enabling the partners to act together

To help raise awareness and create a common plan of work across the LCP partners, training sessions were delivered virtually by the Safer Leeds Domestic Violence Team (a commissioned service that supports people of all genders in Leeds affected by DVA by providing a 24-hour helpline, drop-in service, as well as facilitating access to emergency accommodation),

with support from the LCP development team.

The sessions covered:

- ▶ Domestic abuse and violence awareness training
- ▶ Multi-agency risk assessment conference (MARAC) and domestic abuse, stalking and honour-based violence (DASH)
- ▶ Coercive control
- ▶ Stalking and harassment.

A post questionnaire survey was sent out thereafter to evaluate the training, measure attendees knowledge and confidence levels around the subject after training, and to understand how they were going to use this in practice.

The specific sessions were chosen from feedback ascertained in the pre-consultation phase on 'gaps in knowledge' (this information was collected at the start of the pandemic from conversations with local partners, voting within partnership meetings and through an online survey). By working as a partnership, having conversations and looking at the data, understanding of the issues and each other were gained.

Developing community actions

To develop and embed community actions the following occurred:

- ▶ White ribbon craft packs for the

16 days of action in November (a national campaign to highlight violence against women —

www.whiteribbon.org.uk/) were distributed to partners and organisations in Seacroft and surrounding areas. All partners were able to gift the packs to their families/clients safely

- ▶ A volunteer came up with the idea of the white ribbon craft packs for children and families in the community during the pandemic. The vision was to have card cut out ribbon for families to decorate and display at home, and also to write a pledge card. The pack also included craft material, domestic violence related information and contact numbers for support
- ▶ 300 packs in total were given out (within the LS14/15 postcode), which included all the crafts/information and much more
- ▶ The packs were made up by volunteers at the Cross Gates and Manston Children's Centre ready for the beginning of the November white ribbon campaign (allowing 72 hours quarantine before being given out)
- ▶ All activities were advertised via e-platforms/social network accounts in the cluster and ward areas to update partners and members of the community to join in with the safe activities at

LS14 Trust...

LS14 Trust is a not-for-profit organisation, owned and led by the local community of Leeds 14 (a postcode area within East Leeds). The trust was set up by a group of local people who wanted to work together to change the community that they loved. Their vision is to see LS14 become a welcoming, vibrant, happy place where people feel in control and are proud of their achievements — a place where every resident is safe and respected, i.e. a well-connected community which recognises its power to bring about and sustain positive social change.

home. The campaign also shared information on the local Leeds-based services and support they offer, as well as national support and Covid changes to services in these times

- ▶ Community ambassadors — from listening to professionals and community members, there has been a keen interest to provide training to volunteers and members of the community. Conversations are currently taking place to pilot a community ambassador role in Seacroft with a vision to be city-wide in Leeds. The ambassador would receive bespoke training around DVA, signs of DVA, and what to do
- ▶ Local shops and establishments became involved in sharing information and offering signposting conversations.

Staff and members of the community from Cross Gates Children's Centre commented:

We've been waiting for something like this to get behind for ages.

I have to say I feel our working group is amazing, so inspirational and productive.

The enthusiasm and passion for working together and sharing good practice is immense.

A local peer support group set up by mums stated that:

Tackling domestic abuse is something that we are passionate about, we know family members who have gone through domestic violence so it's been great to link up with

Practice point

Abuse can involve, but is not limited to:

- ▶ Psychological abuse
- ▶ Physical violence
- ▶ Sexual violence/abuse
- ▶ Financial abuse
- ▶ Emotional abuse

(Home Office, 2012)

the LCP. In the future, we are hopeful for better conversations and everyone in the area working better together, making hard conversations easier so that people can confide in each other. Setting up safe spaces in the area is also great, so people know exactly where they can go for help, but it's not obvious that's why you are there.

Thea Stein, chief executive at Leeds Community Healthcare NHS Trust, who is the lead for this work in Leeds, said:

It takes a lot of work to support a LCP and to help members come together to work. The type of work outlined here doesn't happen over night and doesn't happen without commitment, openness and a desire to work together from all partners. Work happens because relationships of trust and openness are formed and that takes work and facilitation and skill. I'm proud to lead the LCP development team on behalf of the city of Leeds and the work outlined here is a brilliant example of what can happen when the hard work starts to pay off. As ever, I am reminded of the Margaret Mead quote: 'never doubt that a small group of committed and thoughtful citizens can change the world. Indeed, it is the only thing that ever has'.

Core learning from this work has been manifold. In the authors' opinion, the following are the leading insights which have been gained.

First, that we are best when we work together with people. The old paradigm of working in silos in separation from other organisations needs to be broken. Partnership and co-creation is the future. Only when social care, NHS, third sector organisations etc come together can the resource needed to most deeply impact and create positive change be created.

Second, that this work is all about people. It is how we work with each other that affects

how we work overall. Listening, understanding each other and building from the stories and hopes of people who live in a community is central to this.

Third, this work has been seen to locate itself in community shops and businesses — places where local people go. This is fundamental to the work and its meaning. The old models of doing work at communities (rather than with and from within communities) has fundamental flaws, as it does not seek to let people create and own solutions where they are.

Other areas of the city are now seeking to learn the elements of how this work of awareness, alliances and actions has started to make a difference in Seacroft.

Community nursing and its teams are essential to this work, and these alliances continue to be developed and built on in Seacroft.

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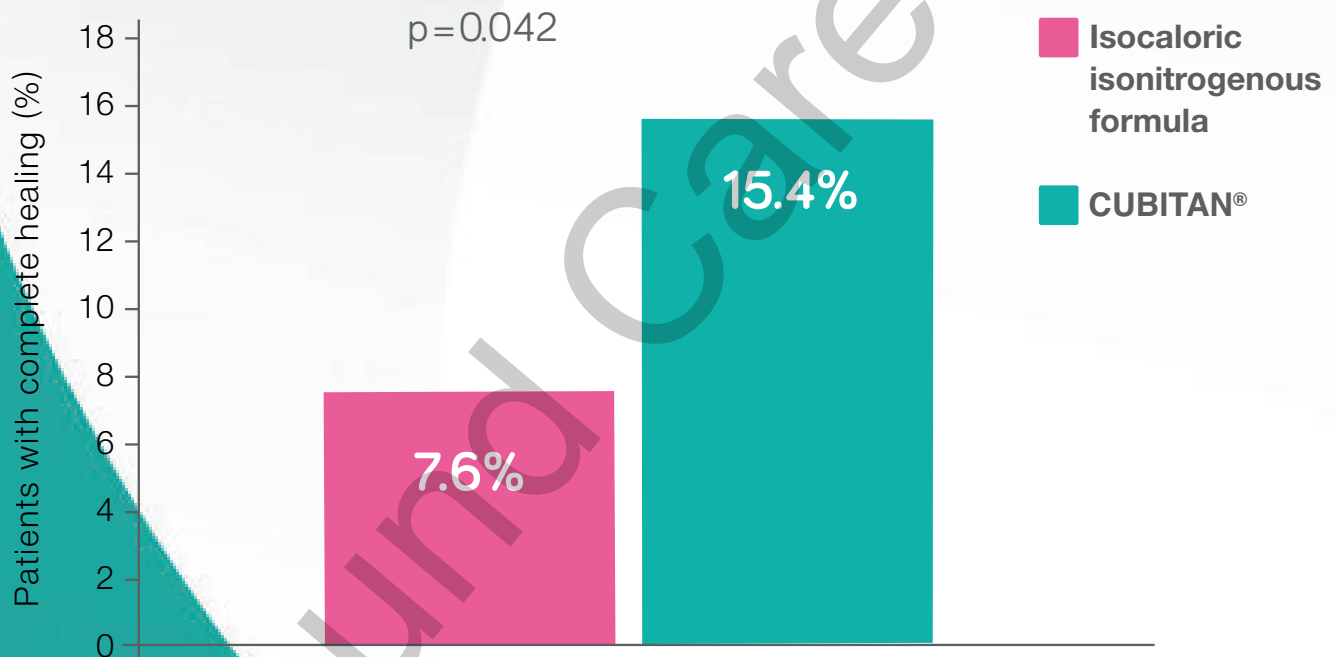
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Reference: 1. Cereda E, et al. Disease-specific nutritional support in malnourished pressure ulcer patients: a randomised, controlled trial. *Ann Intern Med*, 2015; 162: 167-174.

*Product can be provided to patients upon the request of a healthcare professional. They are intended for the purpose of professional evaluation only.

This information is intended for healthcare professionals only.

Cubitan is a Food for Special Medical Purposes for the dietary management of malnourished patients with chronic wounds and must be used under medical supervision.

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NUTRICIA
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This JCN clinical skills series provides a guide to the identification, assessment and management of chronic oedema of the lower limb and associated complications.

Part 1: Chronic oedema explained

This clinical series aims to demystify and simplify approaches to assessment and management of chronic oedema in the community, including the promotion of self-care, with the aim of improving efficiency and delivering the best evidence-based care for patients with chronic oedema. Part 1 explains what chronic oedema is, its prevalence, causes and appearance.

Chronic oedema is an underestimated health problem that remains widely unrecognised despite affecting between 200,000–420,000 men, women and children in the UK (National Lymphoedema Partnership [NLP], 2019). It is a progressive and debilitating long-term condition that requires effective management. It can have a detrimental and profound effect on people's quality of life, health and their ability to engage in normal daily activities, as swelling impedes movement and is painful (Moffatt et al, 2017). Correct management of the condition can greatly alleviate these issues, but many patients receive inadequate treatment or are unaware that treatment is a possibility (Lymphoedema Framework, 2006).

Chronic oedema is commonly encountered in many healthcare settings, especially the community (Atkins, 2014), and its long-term management can place a burden on health services (Moffatt et al, 2019; NLP, 2019). Anecdotal evidence indicates that chronic oedema is a frustrating and time-consuming condition to manage for community practitioners (Todd et al, 2018).

PREVALENCE

Chronic oedema presents a major clinical problem within community nursing services in the UK and is set to become more problematic as the

population at risk of developing it is set to grow (Moffatt et al, 2019).

The prevalence, or number of people with chronic oedema in a health service population is high and is comparable to, or even greater than, the prevalence of other serious long-term conditions, such as stroke (Moffatt et al, 2017).

A survey carried out in 2012 estimated that within the general population of the UK, approximately 3.99 people in every 1,000 have chronic oedema (Moffatt et al, 2017). This is almost three times the previously reported prevalence of 1.33 per 1,000 (Moffatt et al, 2003), and is thought to correlate with the increasing ageing population and associated polymorbidity. In people aged over 85 years, the prevalence of chronic oedema increases to 12 in every 1,000 (Moffatt et al, 2017).

However, it is thought that these prevalence figures are underestimated, particularly in community care settings (Moffatt et al, 2017). This is for a number of reasons:

- ▶ Poor recognition and limited knowledge of chronic oedema among healthcare professionals, particularly nursing home staff
- ▶ Lack of awareness among the general population, so they do not present to health services
- ▶ Development of symptoms late in

the disease process, meaning that early to mid-stage disease is missed.

The challenges that chronic oedema presents to community services are set to intensify. The demographic of the community is changing to include an expanding ageing population. By 2039 there will be 3.5 million people aged 85 years, and many aged over 100 years (Office for National Statistics [ONS], 2017).

As said, this increased longevity also means that many more people are living with polymorbidity. Indeed, it is estimated that nearly three million people are living with three or more long-term conditions, such as cardiovascular disease and diabetes (Department of Health, 2012). The development of chronic oedema is also related to lifestyle choices, such as immobility and obesity, both of which are expected to rise

Practice point

What is the difference between chronic oedema and lymphoedema?

Chronic oedema is an umbrella term that encompasses several causes that lead to oedema formation in any part of the body, and this includes lymphoedema (Cooper-Stanton, 2020).

Practice point

Four people in every 1,000 have chronic oedema. This increases to 12 people in every 1,000 over the age of 85 years (Moffatt et al, 2017).

exponentially in the next 10–15 years (Moffatt et al, 2017).

It is clear that while changing demographics will increase the demand for chronic oedema management, economic pressures will limit growth in funding. Constrained budgets, coupled with increased demand, will put more pressure on community services that are already struggling to cope with demand (Royal College of Nursing [RCN], 2021).

There is a predicted shortfall in the number of healthcare professionals available to deliver care. Therefore, the ongoing challenge now and in the future is how to drive up quality of care despite constraints on funding and fewer available clinicians to deliver it (Dowsett et al, 2014).

Fortunately, improvements in the quality of care delivered can be made with minimal impact on resources; namely, working efficiently with a consistent evidence-based approach to care delivery can free up nursing time to spend elsewhere (Stanton, 2021). Conversely, a lack of appropriate care can lead to increased severity of chronic oedema and the risk of complications with serious consequences, including cellulitis (skin infection), ulceration and lymphorrhoea (also known as wet or leaky legs) (Anderson, 2017).

If the disease is not identified early and becomes chronic, the clinician and patient become locked in a cycle of delivering and requiring complex care respectively, with all the demands on time and resources that involves. Early identification of people at risk of or with chronic oedema, and prompt intervention can prevent the condition progressing and may reduce the need for complex care. It is therefore imperative that clinicians delivering care in the community setting are

familiar with chronic oedema and its management.

The *NHS Long-Term Plan* (NHS England, 2019) puts health promotion and illness prevention at the centre of primary and community care. It also identifies the provision of support for self-management as one of three key approaches to improving services and patient outcomes (NHS England, 2019).

CAUSES OF CHRONIC OEDEMA

Chronic oedema results when fluid builds up in the tissues, as a consequence of an ongoing underlying problem that prevents the venous and/or lymphatic systems from maintaining fluid balance. The lymphatics are responsible for clearing fluid from the tissues and returning it to the circulation (*Table 1*). If this process is impeded in any way, oedema occurs (Levick and Michel, 2010).

Many of the causes of chronic oedema are problems that physically affect the structure and/or the function of the venous and/or lymphatic systems (*Table 2*).

Chronic oedema of the lower limb may result from one or more underlying causes, including venous disease, trauma, infection, or following surgery. It may also be caused by hypoproteinaemia, nephrotic syndrome, limb dependency, heart failure, and obesity (Best Practice Statement, 2008; Newton, 2011; Todd, 2016). As chronic oedema is caused by many different conditions, it is commonly encountered across both primary and secondary care (Moffatt et al, 2017).

WHAT IS CHRONIC OEDEMA?

Chronic oedema is an umbrella term for any swelling that has been present for three months or more (Moffatt et al, 2003; British Lymphology Society

Table 1: Quick revision: the lymphatic system (Mortimer and Rockson, 2014; Knight and Nigam, 2020)

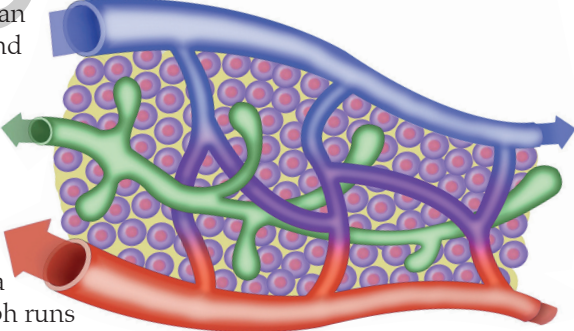
- 
- ▶ The lymphatic system can be thought of as a second circulatory system that runs parallel to, and in conjunction with, the cardiovascular system
 - ▶ Lymphatic vessels form the channels of the lymphatic system, and a watery fluid called lymph runs through them
 - ▶ Lymphatic vessels are structurally similar to veins: they have relatively thin walls and carry lymph under low pressure
 - ▶ Like veins, most of the larger lymphatic vessels are equipped with valves to prevent the backflow of lymph under the influence of gravity
 - ▶ The lymphatic system has three major functions:
 - Tissue drainage
 - Fat transport
 - Immune responses
 - ▶ Lymph vessels return the capillary ultrafiltrate and escaped plasma proteins from most tissues back (ultimately) to the blood circulation
 - ▶ Working in partnership with the cardiovascular system, the lymphatics are responsible for maintaining tissue (and plasma) volume homeostasis
 - ▶ Oedema can be defined as an over-accumulation of fluid in the interstitial spaces, which leads to visible swelling of the soft tissues
 - ▶ Because oedema is subject to gravity, it becomes more apparent in the distal regions of the lower limbs and is often particularly noticeable in the ankles and feet

Table 2: Causes of chronic oedema

- ▶ Overload: venous system malfunction leads to fluid overloading the lymphatics resulting in failure
- ▶ Insufficient lymphatics: congenital abnormality can result in the absence of some lymph vessels from birth, or treatment of disease may require the surgical removal of lymph nodes
- ▶ Obstructed lymphatics: lymph nodes or vessels can become obstructed by benign or cancerous growth
- ▶ Abnormal lymphatic contractability: the lymph vessels do not move fluid as well as they should
- ▶ Trauma to lymphatics: damage may occur to the lymphatic system as a result of surgery or trauma
- ▶ Obesity: extra weight in the abdomen can put undue strain on the lymph vessels
- ▶ Immobility: puts undue strain on the lymph vessels
- ▶ Chronic venous hypertension: resulting from failed or damaged valves in the leg veins, can lead to pooling of blood in the legs, resulting in oedema (BPS, 2008; Newton, 2011; Todd, 2016)

assessment have been comprehensively described by Mahoney (2020) and is not a subject for this article.

A recent study identified that effective management of lower limb oedema, for example by using compression therapy, reduced the risk of wound development and should be an essential component of an holistic approach (Burian et al, 2022).

Healthcare professionals responsible for diagnosis and treatment planning should either have capabilities/competencies for managing chronic oedema, or be able to refer to specialist services for specialist input (NWCSP, 2020). **JCN**

[BLS], 2019). It is a progressive condition that can range from mild (Figure 1) to moderate swelling (Figure 2), to extremely swollen limbs with distorted shape (Figure 3) and skin changes.

As the condition progresses, there is the potential for further complications such as recurrent cellulitis and lymphorrhoea (leakage of lymph fluid through the skin of the lower limbs). However, as said above, many of these complications can be avoided by early identification and management (Anderson, 2017).

CHRONIC OEDEMA AND WOUNDS

Lower limb chronic oedema and wounds often occur together (National Wound Care Strategy Programme [NWCSP], 2020; Stanton, 2021). Chronic oedema is not directly responsible for leg ulcer development, but its presence reduces oxygenation of tissues, potentially delaying healing (Stanton, 2021). Moffatt et al (2019) also reported a significant association with chronic oedema and the presence of a wound. It was reported that between 52% and 69% of patients cared for by community nurses had chronic oedema, and of these, 73% also had a leg ulcer.

If a wound is present (Figure 3), wound assessment should take place. The components of wound



Figure 1.
Mild oedema.



Figure 2.
Moderate oedema.

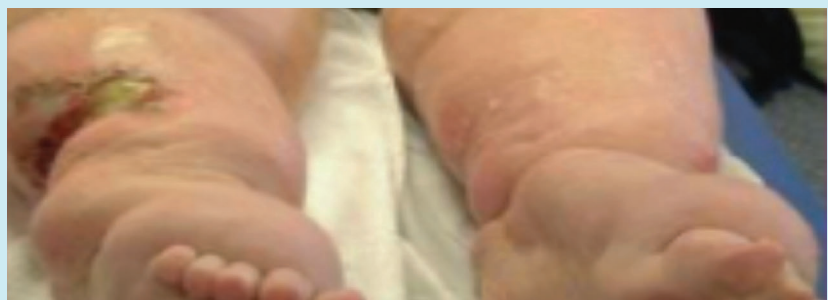


Figure 3.
Severe oedema extending to feet and resulting in irregular limb shape.

Remember...

- ▶ Oedema or swelling is part of the body's natural response to injury; this type of swelling will resolve as recovery occurs within a short time frame
- ▶ Chronic oedema is swelling that has been present for at least three months.

Wound Care People, 2019

Part two in this series will examine chronic oedema assessment using the six Ss': story; self-care; site; skin; size; shape.

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Revalidation Alert

Having read this article, reflect on:

- Your knowledge of the lymphatic system
- Your ability to recognise mild, moderate and severe chronic oedema in your patients
- The number of people in your caseload that could have chronic oedema
- How often you see lower limb chronic oedema in conjunction with a wound.

Then, upload the article to the free JCN revalidation e-portfolio as evidence of your continued learning: www.jcn.co.uk/revalidation

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KEY POINTS

- Chronic oedema is the term used to describe swelling that has been present for longer than three months.
- It is a progressive and debilitating condition that requires long-term management.
- The prevalence of chronic oedema is currently equal to, or greater than, that of other long-term conditions, such as stroke.
- The number of people with chronic oedema is set to increase as the older population, and associated polymorbidity, grows over the coming years.
- Increased awareness of, and vigilance for, the signs and symptoms of chronic oedema can help to identify the condition in its early stages, leading to early intervention and prevention of complications.

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Seven aetiologies of MASD: devising a protocol for improved care

Kirstie Atkinson, Louise Lodge, Cathryn Todd, Helen Lawson, Sandra Smyth

Moisture can affect the normal function and permeability of the skin, leaving our bodies susceptible to infection. The damaging effects of moisture-associated skin damage (MASD) impact a wide range of patient groups, however, wounds caused by moisture are often mistaken for and treated as if they are pressure ulcers. Moisture can come into contact with the skin from a number of sources, but damage can be treated in the same way, despite its cause. In the authors' clinical opinion, if nursing staff are able to identify and treat skin damage correctly according to its aetiology, faster rates of healing, improved quality of life, and fewer resources used on wound care would be seen. This article looks at the identification of seven aetiologies of MASD following an audit, and the subsequent development and implementation of a protocol to improve and standardise skin care in the authors' trust, which it was hoped would provide a dynamic and unified approach to the management and education of MASD.

KEYWORDS:

- Moisture-associated skin damage
- Seven aetiologies
- Implementing a new protocol
- Innovation
- Education

Moisture-associated skin damage (MASD) is an umbrella term to describe clinical conditions in which the skin's integrity is compromised by prolonged exposure to moisture (see below). Once skin is over hydrated, physical damage, including friction and shear, is more likely to occur. This can result in painful damage, such as maceration, erosion, erythema and bleeding, which subsequently affect patient quality of life (Beeckman et al, 2015).

The damaging effects of moisture to the skin are well documented (All Wales Tissue Viability Forum and All Wales Continence Forum, 2014). The most common form of MASD, which

Kirstie Atkinson, tissue viability project nurse specialist; Louise Lodge, tissue viability project nurse specialist; Cathryn Todd, tissue viability nurse specialist; Helen Lawson, tissue viability assistant practitioner; Sandra Smyth, district nurse lead, all at County Durham and Darlington NHS Foundation Trust

'It is important that healthcare professionals understand the risk factors for skin breakdown and how to assess and manage different types of MASD.'

results from urine (incontinence-associated dermatitis [IAD]), is a risk for the estimated 14 million people experiencing incontinence in the UK (Lumbers, 2019). However, in the authors' clinical experience, MASD does not seem to be as well understood by nursing and care staff, and is often treated in the same way regardless of its aetiology, or mistaken for and treated as pressure damage. Moisture damage requires different interventions to pressure damage, and thus correct identification of underlying aetiology is essential (Mahoney, 2019).

HOW MASD HAPPENS

The stratum corneum — or epidermis — protects the body from any potential pathogens because of its normal marginal acidity, which provides a protective layer. The 'acid mantle' of the skin is between 4–6pH, which supports the commensal bacteria of the skin (Flanagan, 2013). If this layer is compromised by any means, pathogens can enter the body. Prolonged or continuous exposure to moisture, no matter the source, decreases the skin's normal barrier function and permeability. This increases the risk of the stratum corneum becoming damaged, therefore increasing the risk of infection (Zulkowski, 2012). In some cases, the skin can break down extensively, as a result of erythema and maceration, and cause the development of moisture lesions.

MASD is commonly found in continence care, however, it is also encountered in many different patient groups. Due to this, MASD is used as an umbrella term to describe the spectrum of damage that occurs in response to the prolonged exposure of moisture to the skin. The four clinical manifestations are:

- ▶ Incontinence-associated dermatitis (IAD)
- ▶ Periwound moisture-associated dermatitis (resulting from wound exudate)
- ▶ Intertriginous dermatitis (intertrigo, resulting from sweat)
- ▶ Peristomal moisture-associated (affecting the site of a stoma and surrounding area).

It is important that healthcare professionals understand the risk factors for skin breakdown and how to assess and manage different types of MASD. Having a good understanding will help them to

implement preventative measures to protect and restore the skin's barrier function through a good skin-care regimen, thereby reducing the incidence of MASD (Wound Care Today, 2015).

With this in mind, the authors set about understanding the causes of MASD to help nurses and care staff better understand how to recognise and treat the condition and its various causes, i.e. promoting a proactive rather than reactive response to care.

DEVISING THE AETIOLOGIES

Patient with recurrent MASD

The seven aetiologies were devised following a multidisciplinary approach to the care of a patient within the community. This patient repeatedly suffered from moisture damage due to constant perspiration after an impairment to the hypothalamus.

The brain's hypothalamus is responsible for maintaining homeostasis. It therefore responds to any bodily changes in the appropriate manner, whether this is through regulating emotions, sleep, feeling full and even temperature control. Due to its fundamental role, damage to the hypothalamus can cause a vast series of complications and disorders (Mandal, 2019). As a result of this patient's condition their temperature had to be externally regulated, they also received ongoing treatment for moisture and care for other medical conditions, all of which impacted on their comfort and quality of life.

During this episode of care, a wide range of treatments and prevention methods had been tried to treat the patient's moisture lesions by members of the multidisciplinary team before being referred to the authors' team due to non-healing wounds. This included the use of barrier creams, ointments, sprays, emollients, dynamic mattress, cushions and even bed rest. It was also discovered by the staff within the trust that all moisture damage was being treated in the same way, regardless of the cause.

Despite these interventions, the patient's wounds were not healing. Reflecting on this and employing clinical expertise and experience, the authors' team tried to find if there were other causes for the moisture lesions.

Prevalence audit

Following this episode of care, a prevalence audit was conducted on all moisture lesions identified and reported through the trust's incident reporting.

The authors' trust receives a daily report with details of moisture lesion incidence within the previous 24 hours. The report provides evidence and characteristics of these occurrences, e.g. anatomical locations of the moisture damage and what characteristics have been identified. These reports may also include details on the source of the moisture and treatment plan (NHS England, 2019). Information was extracted from these reports by the authors and their team and compiled into a database.

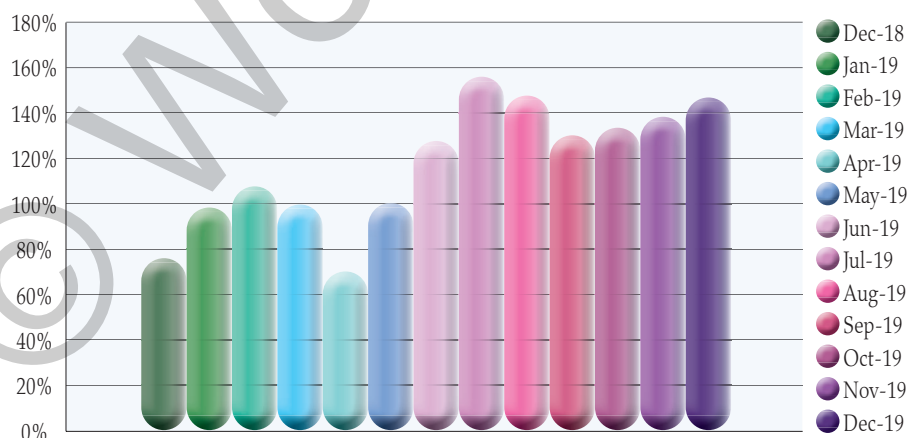


Figure 1. Monthly comparison of incidences of MASD throughout the trust.

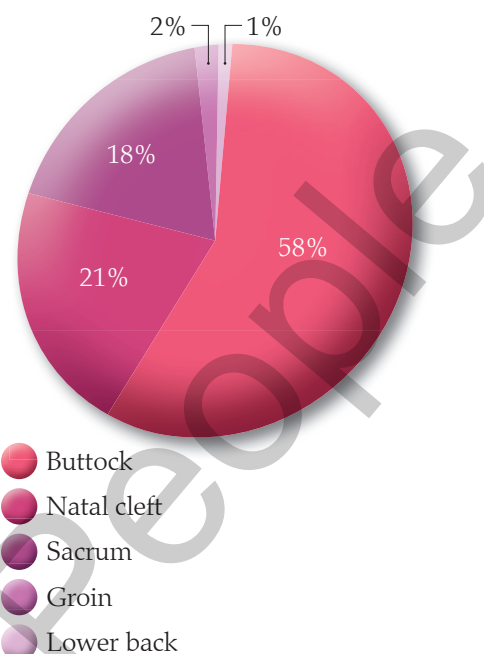


Figure 2. Areas of the body most affected by MASD, as detailed in the trust's incident reports.

From the data, there were an average of 157 incidents of moisture damage reported each month. A relationship was also determined regarding seasons, with higher incidents of moisture damage being recorded in both the summer and winter months. Figure 1 shows the monthly comparison of incidences of MASD throughout the trust.

The areas of the body found to be most likely to suffer from moisture damage were the sacrum, buttocks and anal cleft. These are areas that would be affected in cases of incontinence, but also areas more exposed to perspiration. Figure 2 shows the locations most affected by moisture damage.

SEVEN AETIOLOGIES

Through analysis of the incident reports, the authors and their team identified that there were seven main causes for MASD, i.e:

- ▶ Acute
- ▶ Chronic
- ▶ Mechanical
- ▶ Faecal
- ▶ Organic
- ▶ Stomas
- ▶ Moisture-associated dermatitis/intertrigo.

Table 1: Seven aetiologies of MASD: causes identified in the authors' trust's prevalence audit

Aetiology	Presentation
Acute	A short-term illness, or exacerbation of chronic illness that causes excessive moisture to an area of skin (Hunter, 2009). This could include a urinary tract infection (UTI), gastrointestinal infection, fever, or an exacerbation of Crohn's disease/inflammatory bowel disease. Moisture could include urine, perspiration, or faeces in constant contact with areas of skin, for a short period of time
Chronic	Urinary incontinence of a duration of at least six months. Urine is in constant contact with skin for a prolonged period of time
Mechanical	Factors that increase moisture on a patient's skin, not related to illness or incontinence. These could include saliva (drooling), mucus, sweating, poor hygiene, wound drainage, obesity, and malnutrition. Moisture could include saliva, mucus, perspiration and wound exudate. Patients who are obese may have increased skin folds, and be less mobile, or less able to maintain effective skin hygiene (Earlam and Woods, 2020). Nourishment is known to be a significant factor in maintaining skin integrity, and malnourished patients will have increased vulnerability to skin damage (Leaker, 2013). Unwashed skin can harbour bacteria and germs, therefore poor hygiene is also a risk factor (NHS, 2021)
Faecal	When the skin has come in contact with faecal matter, including episodes of diarrhoea, overflow, faecal incontinence and those unfortunate incidents where patient hygiene needs have not been met, causing irritation to the skin
Organic	Excessive moisture caused by the body, and/or organs of the body. Sources of moisture would include perspiration, serous fluid, and excessive wound exudate. Patients may be suffering from hypothalamus disorders, cancers, hypoalbuminemia, neurological disorders, oedema/lymphoedema, or hyperhidrosis (abnormally excessive sweating) — all of which affect the body's moisture production (Das, 2020), and the skin's resistance to it
Stomas	Excess moisture around a stoma site, due to ill-fitting equipment or devices. Moisture would include urine, faeces, liquid feed, and saliva. Specialist knowledge is required for the management of this type of moisture damage, as there is multiprofessional involvement, all requiring differing treatment options
Moisture-associated dermatitis/intertrigo	An inflammatory response to excess moisture on the skin. Sources of moisture would include urine, faeces and perspiration. Treatment to address inflammation is required as well for the moisture damage to the skin (Beele et al, 2018). Intertrigo is moisture damage to skin folds, where infection may also be present. Treatment needs to remove moisture, as well as treat any infection present

An explanation of these aetiologies is given in *Table 1*.

Although the different types of moisture damage may present in similar ways, different causes require different methods of management. In the authors' clinical experience, educating healthcare professionals to identify the cause of moisture, promotes more effective treatment and can also result in preventative strategies being implemented to lessen the risk of further damage occurring.

Implementation

Following identification of the seven aetiologies, a protocol was developed by the authors and their team, together with the district nursing team within the community services, as a working pilot to help facilitate the care and management of moisture lesions and assist in the education of healthcare professionals. The aetiologies were included within the protocol.

The district nurses were enthusiastic about the project, as they felt it would help both to reduce incidence and prevent moisture lesions, while also informing treatment. The seven aetiologies are not only easy to understand, but also

give staff the confidence to manage or prevent moisture lesions once the aetiology is identified.

The seven aetiologies of MASD and the protocol is to be implemented across all nursing homes, residential homes and domiciliary care agencies within the trust's region. District nurses were also to implement the moisture lesion protocol, which provides information on the choice of products and treatment plan dependent on the level of moisture damage a patient is experiencing. Initially, one district nurse base would trial the moisture lesion protocol, which will then be phased out to all district nurse bases and implemented throughout all nursing and residential homes and domiciliary care agencies. Education will coincide with the implementation of the protocol. The wound care industry will also be involved with the promotion and resources for the rollout of the moisture lesion protocol.

Feedback received

Sandra Smyth, the lead for the district nurse team involved in the innovation, commented on the seven aetiologies of MASD and the associated pilot protocol:

As a district nursing team, we

work closely with care home staff to ensure the safe and effective care of residents. In Barnard Castle, we do not have any nursing home beds: all care home residents are supported by the district nursing team.

Due to an increase in training, most care homes were aware of the causes of pressure damage, but unfortunately this led to them recording every area of skin damage or loss to the buttocks or sacrum as pressure damage. They used this terminology and often requested pressure-relieving equipment to prevent further damage. This could have led to pressure-relieving equipment being ordered at a cost to the NHS.

When a proactive assessment, including that of the skin, was completed, the district nurses quickly identified that the skin loss, which was related to moisture damage, was being wrongly labelled as pressure damage. We were finding residents had skin loss to areas that are not related to pressure — in the natal cleft or having a kissing buttock appearance — these residents were usually




THE S.M.A.R.T. APPROACH TO MOISTURE-ASSOCIATED SKIN DAMAGE

Identify and report MASD appropriately.

In line with NHSI guidelines²



Moisture-Associated Skin Damage (MASD) is caused by overhydration of the skin from perspiration, incontinence, wound exudate, hypersalivation.

PREVENT/RESTORE	PROTECT	PROTECT/REPAIR	REPAIR
Skin Care for Incontinence Patients <ul style="list-style-type: none"> Cleanse using a pH balanced cleanser or emollient Pat skin dry Apply appropriate barrier product to protect skin from moisture and irritants, protect from further injury and to allow restoration of the skin barrier Complete Datix/Incident report 	 <p>MILD* Skin Damage from Incontinence</p> <p>Erythema (redness) of skin only Dry and intact but irritated and at risk of breakdown¹ Apply barrier cream every 3rd wash/twice a day OR Apply barrier film once a day</p>	 <p>MODERATE* Skin Damage from Incontinence</p> <p>Moderate Erythema Less than 50% damaged skin Oozing and/or bleeding may be present¹ Apply barrier film once a day</p>	 <p>SEVERE** Skin Damage from Incontinence</p> <p>Large area of Erythema More than 50% damaged skin Oozing and/or bleeding may be present¹ REFER TO TVN, CONTINENCE NURSE OR GP</p>

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incontinent, wore incontinence products, and more often than not were mobile.

We would try to educate on the importance of skin hygiene during visits, including details on how to wash and dry skin to prevent moisture damage. There have been trends to use wet wipes, which has meant skin remains damp when the incontinence pads are applied. This, in turn, leads to superficial skin layers being removed when the pad is pulled down or adjusted. All of this leads to skin breakdown.

We felt that educating about simple washing and drying of skin was taken as demeaning to staff — almost as if we were accusing them of not being able to perform the most simple of tasks, which was not the case.

To add further challenge, there were myriad creams to choose from, all of which claimed to act as a barrier cream against moisture. We were battling against personal preferences, GP choice, and whether it had been bought at the local chemist (and therefore dependent on which company representative had been visiting).

Having the protocol has allowed us to develop a unified approach to moisture damage, which starts from the basics of good skin hygiene. The choice of product to escalate through is clear and simple. It allows all healthcare professionals involved to follow the same route, from hygiene

basics, to prevention and healing. The beauty of the protocol is that the route to care is dynamic. The choice of product can be changed depending on the skin condition. It is hoped that this will allow a move back to simple, good skin hygiene, without any product needed, thus leading to financial savings.

CONCLUSION

With MASD causing damaging effects to the skin, a unified approach needs to be adopted by nursing staff. By helping healthcare professionals to understand the different types of moisture damage, it is hoped that they will be better equipped with knowledge and skills to act in a preventative manner, resulting in as little impact and harm on patients as possible. In turn, by treating skin damage appropriately, there will be reduced waste and cost.

The aim is that the seven aetiologies of MASD will provide this knowledge and skill base to practitioners, which will ultimately lead to financial savings as an added positive. **JCN**

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Did you know...

Obesity carries an increased risk of intertriginous dermatitis (damage caused by sweat). This is a result of excessive skin folds, increased perspiration to regulate body temperature, higher skin surface pH (Man et al, 2009), and a thinner dermal layer and decreased collagen content (Tobin, 2017).

Use of syringe drivers for symptom management at the end of life

Tara Bright

A syringe driver is a device used for administering medications subcutaneously to patients in a range of healthcare settings (Dickman and Schneider, 2016). However, this device is most commonly used in palliative and end-of-life care, which this article will focus on. They are small, battery-operated devices allowing portability and discretion, which are placed under the skin (subcutaneously) and typically infuse medication over 24 hours before requiring replenishment (Marie Curie, 2021). Using a syringe driver does not always signify that a person has reached the last days of their life. Instead, they function as a convenient method of administering medication for those patients who are unable to take prescriptions orally. The Scottish Palliative Care Guidelines (2020) explain that their use is valuable for patients who are experiencing bowel obstruction, malabsorption, nausea, vomiting, dysphagia or reduced consciousness, such as that seen towards the end of life.

KEYWORDS:

- Community nurses
- Palliative care
- Syringe driver
- Symptom management

COMMUNITY NURSE'S ROLE

Ali et al (2015) highlight the importance of identifying what a patient's preferred place of death is. Without having these conversations, patients are statistically more likely to end up being taken into hospital to die, which may be against their wishes. Research carried out by Dying Matters (2014) found that almost 70% of patients would choose to die at home. Community nurses thus have an essential role in ensuring that patients have access to palliative care as early as possible in their care journey (Moreland et al, 2021). Further research from Ramplin (2019) explains that because of their unique role and the

relationships they form with their patients, community nurses are best placed to support those wishing to die in their own homes.

Palliative care aims to take a holistic approach to improve patient quality of life, ultimately by reducing suffering (Hartogh, 2017). While palliation encompasses psychological, social and emotional factors, physical symptoms are often those which cause both the patient and those around them the most distress and anxiety (Nunn, 2014). Pain is often considered the obvious symptom to treat. However, symptom management in palliative care is broader and most commonly aims to treat:

- ▶ Delirium and anxiety
- ▶ Breathlessness
- ▶ Respiratory secretions
- ▶ Nausea and vomiting
- ▶ Pain (Thomas and Barclay, 2015).

This article focuses on each of these symptoms from

a pharmaceutical treatment standpoint, examining how syringe drivers can be used in the community. However, it is important to note that before a syringe driver is needed, there are a range of other non-pharmaceutical treatment options which may be encouraged by healthcare professionals, for example, for pain, treatment options may include massage or relaxation therapy.

DELIRIUM AND ANXIETY

When managing palliative patients, the goal is often to keep them settled and comfortable. However, many patients towards the end of life experience delirium, which can be described as a neurological disturbance in their awareness leading to particular symptoms (Grassi et al, 2015). Guidance from the BC Centre for Palliative Care (2019) explains that delirium can be variable, with some patients experiencing hyperactivity and restlessness, whereas others will experience hypoactivity and drowsiness, or even a combination of both. Typically in palliative care, this symptom is managed with a benzodiazepine (Hui, 2018). Initially, sublingual lorazepam can be effective, but as the patient enters an unconscious stage of dying, medications such as midazolam become useful as they are administered subcutaneously via the syringe driver (Chand, 2013; National Institute for Health and Care Excellence [NICE], 2019).

BREATHLESSNESS

Breathlessness has been regarded as one of the most challenging symptoms in palliative care (Crombeen and Lilly, 2020). It is difficult to manage and frightening

Tara Bright, community staff nurse,
Dorset Healthcare University Foundation Trust

Table 1: Advantages and disadvantages of using syringe drivers (Barnes et al, 2009; Mitchell and Elbourne, 2020)

Advantages	Disadvantages
Two or more drugs can be mixed to manage multiple symptoms at the same time	Staff require specialist training to use a syringe driver
The need for invasive injections to manage symptoms is reduced	Some medications can cause reactions around the site where they are placed
Medication is given at a continual rate so there are no peaks and troughs in its delivery, aiming to keep symptoms under constant control	Certain drugs are not compatible with each other, or cannot be given subcutaneously
Effective for those patients who can no longer take oral medication	Syringe drivers require community nurses to visit daily if the patient is to remain at home

for those experiencing it, as well their family/friends (Gillon and Clifton, 2019). Breathlessness is most common in patients experiencing end-stage respiratory conditions, such as chronic obstructive pulmonary disease (COPD) or interstitial lung disease (ILD). However, it is a common end-of-life symptom, so community nurses have a fundamental role in recognising and treating breathlessness towards the end of life (Pickstock, 2017).

One of the first-line treatments for breathlessness is oxygen therapy, which may be used to improve hypoxaemia (a lower than normal arterial blood oxygen level) (Kochovska et al, 2021). While oxygen therapy is used as first-line treatment and often keeps patients comfortable, there is little evidence which supports that this actually clinically improves breathlessness (Chin and Booth, 2016). During the last few days of life, patients may require the assistance of a community nurse and a syringe driver to administer opioids to reduce breathlessness. Hui and Bruera (2020) used a randomised control trial (RCT) and found that there is evidence to support the use of short-acting opioids on breathlessness. However, this is still a subject for further exploration.

RESPIRATORY SECRETIONS

Respiratory secretions can also be known as the ‘death rattle’, which occurs at the very end of life as the body loses the ability to manage and swallow any upper respiratory tract secretions produced (MacLeod and Van den Block, 2020). When family members experience their loved ones showing symptoms of

increased respiratory secretions, it can be very distressing (Shimizu et al, 2014). Typically, these secretions can be managed through simple repositioning, as well as pharmaceutically with a syringe driver. Medications such as hyoscine hydrobromide or glycopyrronium bromide are used for this purpose, and there is now research to suggest that administering hyoscine pre-emptively can reduce the likelihood of patients developing excess secretions (Mercadante et al, 2018).

NAUSEA AND VOMITING

Nausea and vomiting can occur in palliative care either together or in isolation. However, the processes which cause these symptoms do overlap (Wickham, 2020). Leach (2019) notes that it is important to assess the patient to establish what the cause of their symptoms may be, as this could be reversible. For example, if nausea or vomiting is due to a medication, this could be adjusted or changed by the prescriber. However, if the symptoms are caused by the disease process itself, this may be more complex to resolve.

Nausea and vomiting should be managed holistically in palliative care and, if appropriate, other methods such as oesophageal stenting may be used (Keeley, 2020). However, as disease progresses, it may become necessary to treat the symptoms pharmaceutically using a syringe driver. There are a variety of medications that may be used in a syringe driver. However, it should be recognised that these must only be subcutaneous compatible drugs, such as metoclopramide, cyclizine, levomepromazine or haloperidol, for example (NICE, 2021).

PAIN

Pain continues to be one of the most difficult symptoms for healthcare professionals to treat, especially for patients who are nearing the end of life (Sholjakova et al, 2018). Current guidelines from the Greater Manchester Health and Social Care Partnership (2019) highlight that to manage pain effectively, a detailed assessment should be carried out as patients may have multiple types of pain occurring in different areas of their body, which can be variable in intensity or duration. Clinical guidance from NICE (2016) outlines that opioids such as morphine are the principal treatment for advancing diseases and palliation, and doses for these need to be individually titrated for each patient. *Figures 1 and 2* provide a pain management guide presented by the World Health Organization (WHO, 2018). A syringe driver maintains a constant level of medication in the plasma, meaning that pain levels are more constantly controlled without an increase in pain once the medication wears off (Doherty and Watson, 2015). Therefore, the role of the community nurse is crucial in providing symptom management and keeping patients pain-free and comfortable at the end of life.

By examining the symptoms outlined above, the author has begun to describe some of the medications that a community nurse may use in a syringe driver. However, it should be noted that these medications and their dosages will vary between patients and it will ultimately be down to the decision of their prescribing professional.

The T34 syringe driver, which was previously known as the McKinley, is mainly used in the UK. In the author’s clinical opinion, community nurses should all receive in-depth

▼ Remember...

All anti-emetic medications should be compatible with the other drugs administered in the syringe driver, and this should be checked by the patient’s prescriber.

training and guidance before using a syringe driver. The Royal Marsden ‘Manual of Clinical and Cancer Nursing Procedures’ (Lister et al, 2020) provides a comprehensive step-by-step guide. Before prescribing a syringe driver for use in the community there are an array of things to consider. For example, the prescriber must have accurate knowledge and understanding of how medications work when mixed and if they are compatible with each other (Dickman et al, 2017).

Typically, a 23-gauge butterfly needle is used for administering medications into the subcutaneous tissues using a syringe driver (Mukoreka and Sisay, 2015). Community nurses should ensure that the needle is placed in the most comfortable area for the patient. Common areas include arms, abdomen, thighs, scapula or the chest wall (Gabriel, 2015). Mukoreka and Sisay (2015) explain that when treating distressed, confused or agitated patients, placing the cannula around the scapula may reduce the risk of it being removed accidentally.

Areas which should be avoided for cannula placement include:

- ▶ Bony prominences — there is less subcutaneous tissue for medication absorption
- ▶ Near a joint
- ▶ Near an inflamed site that has previously reacted to medications
- ▶ Lymphoedematous sites, as medication absorption would be reduced

Practice point

Questions to ask regarding pain:

- ▶ Where is the pain coming from?
- ▶ How would you describe your pain?
- ▶ How long does the pain last?
- ▶ How severely would you rate your pain out of 10?
- ▶ Is there anything that makes the pain better or worse?
- ▶ Have any medications or treatment methods previously helped your pain?

(Greater Manchester Health and Social Care Partnership, 2019)

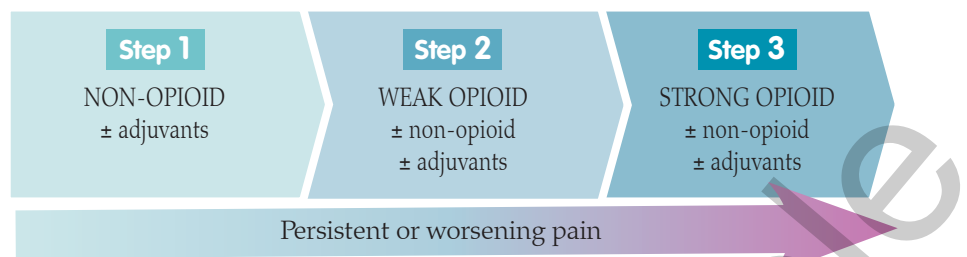


Figure 1. WHO three-step analgesic ladder with examples.

Example	Step 1	Example	Step 2	Example	Step 3
	Start regular paracetamol ▶ Usual dose 1g four times a day, but dose reduction is advisable in many palliative care patients and/or NSAID, e.g. ibuprofen, naproxen or celecoxib	If pain persistent or worsening ▶ Stop paracetamol if not helping pain ▶ Start codeine 30–60mg four times a day regularly		On maximum paracetamol and codeine, persistent or worsening pain ▶ Stop paracetamol if not helping pain ▶ Stop codeine ▶ Commence strong opioid, e.g. oral morphine	

Figure 2. Example of use of the WHO analgesic ladder.

Figures 1 and 2 are taken from Greater Manchester Health and Social Care Partnership (2019) which was developed from the WHO (2018) Guidelines for the Pharmacological and Radiotherapeutic Management of Cancer Pain in Adults and Adolescents.

- ▶ Near any obvious tumour sites (Mukoreka and Sasay, 2015).

Not all medications are suitable for use subcutaneously, as they may cause a skin reaction. Brocx and Cleaver (2012) and Dickman and Schneider (2016) found that cyclizine and levomepromazine lead to a higher incidence of patients having site reactions. If a site reaction occurs, the site may need to be changed more regularly, but this should be monitored daily by the community nurse visiting the patient (Mitchell et al, 2012).

There are many misconceptions surrounding the use of syringe drivers. For example, families of patients often believe that they are used as a last resort and that they are likely to reduce the amount of time the patient has to live. However, this is not the case, so medical practitioners and community nurses must spend time explaining the procedure to patients and their families (Bowers et al, 2019).

As said, community nurses are pivotal in many patient’s care and are often the first point of contact, making them well versed in initiating conversations surrounding palliation and syringe drivers (Royal College of Nursing [RCN], 2019).

PATIENT STORY

During her first year as a community nurse, the author underwent training to administer medications via a syringe driver. She cared for several patients under the supervision of another qualified nurse before being able to see patients alone. The first patient the author ever set up a syringe driver for will be a story that she continues to carry with her for the rest of her nursing career.

The patient she attended was very loved by those around her and had many family members at her bedside ensuring her every need was met. As she had had many hospital admissions, it was decided that she would return home for palliative

Practice point

Community nurses see patients on a regular basis and begin to know the wishes of the patients and their families. Therefore, due to the rapport they establish, they are well placed to initiate difficult conversations giving patients the opportunity to plan their future palliative care. This is known as advanced care planning.

care. The community nursing team had met this patient multiple times throughout her journey and were able to build up a rapport with her family members.

The patient's condition soon deteriorated and a syringe driver was required for symptom management. As this occurred during a weekend, there were few other medical professionals available, so the author became the initial point of contact and support for the patient and her family. When she initially discussed the prospect of using a syringe driver the family were afraid of this as an option, as they felt it would ultimately lead to an earlier death. By taking the time to explain the procedure to those involved, everyone felt more understanding towards the situation and understood that a syringe driver would be the best option for symptom management. The author was able to take time to listen to each person's wishes and enabled the patient to be managed in her preferred place of death, at home.

Each person felt included and part of all decisions. This was especially helpful once the patient had further deteriorated because the author was able to speak to the family members and find out how the previous syringe driver dosing was managing the patient's symptoms. This allowed further insight when deciding whether medications needed to be titrated.

Following the patient's death, the family were extremely thankful that they were able to be part of her peaceful death, which reminded the author again of how the use of a

syringe driver can lead to a positive and fulfilling end of life experience.

CONCLUSION

Palliative care and end of life is a time that is important for both patients and their loved ones. Community nurses can assist in providing a dignified and comfortable end to a patient's life, and this role is one that many community nurses feel honoured to be able to undertake. Often the use of a syringe driver becomes crucial in managing symptoms associated with end of life. Community nurses need to be adequately trained to provide this service and should feel confident in ensuring advanced care planning discussions take place. As end of life care moves out of the traditional hospital setting, use of syringe drivers and symptom management will become a more prominent part of community nurses' ever-evolving role. **JCN**

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KEY POINTS

- Community nurses have unique relationships with their patients and are well placed to initiate end-of-life discussions and advance care planning.
- Syringe drivers are useful in being able to appropriately manage a patient's symptoms at the end of their life.
- Community nurses need to be appropriately trained to administer medications via a syringe driver.
- Many patients are opting for home as their preferred place of death, therefore community nurses need to be well prepared to facilitate this.
- Community nurses can assist in providing a dignified and comfortable end to a patient's life — a role that many feel honoured to be able to undertake.

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Revalidation Alert

Having read this article, reflect on:

- How you ensure that patients have access to palliative care as early as possible
- Symptom management at the end of life
- Your knowledge and experience of using syringe drivers.

Then, upload the article to the free JCN revalidation e-portfolio as evidence of your continued learning: www.jcn.co.uk/revalidation

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Wound care service development over a five-year-period of national change: role of partnership working and education delivery

Rachel Sweeney

This article outlines the development of a community tissue viability service over the same five-year-period in which a number of national issues with wound care were identified through research. These included a lack of evidence-based practice, a changing community workforce and an unwarranted variation in care attributed to a lack of education and training among generalist practitioners. The author describes how a proactive approach was taken to local service development to address these issues, and how partnership working with both colleagues and industry enabled improved wound care education delivery and uptake among a generalist community workforce. These measures resulted in a reduced spend on wound care dressings year on year, despite a predicted trend for increasing costs nationally.

KEYWORDS:

■ Community wound care ■ Generalist practitioners
■ ONPOS ■ Link nurse ■ Education and training ■ Partnership

The last five years have seen a number of changes in national healthcare delivery in England that have undoubtedly impacted upon the way in which wound care is delivered. *Five Year Forward View* (NHS England, 2014) saw the shift of healthcare services, including wound care, into the community setting. Subsequently, Guest et al (2015) determined that approximately 2.2 million wounds were managed annually by the NHS at an estimated cost of £4.5–5.1 billion, with the majority of these costs incurred in the community as a consequence of nursing visits (Guest et al, 2015) (Table 1).

Guest et al (2015) also highlighted unwarranted variation in wound care practice in the UK. For example, approximately 30% of wounds in the study year lacked a differential diagnosis, and only 16% of patients with a leg or foot ulcer had a Doppler ultrasound, despite this being a recommendation for best practice in national guidelines (Scottish Intercollegiate Guidelines Network[SIGN], 2010; Guest et al, 2015). Guest et al (2015) attributed this to the practical difficulties experienced by non-specialist healthcare professionals in the community. They concluded that there was a need for specialist referral to obtain a differential diagnosis and management plan, and that training of non-specialist clinicians in the fundamentals of wound management, including product selection, was vital to improve patient outcomes and reduce costs (Guest et al, 2015).

Gray et al (2018) identified similar marked variations in wound care delivered in the

community in their survey across eight community services in five Northern England trusts. The authors found that there was under use of evidence-based practices, such as Doppler ultrasound and compression use, and overuse of practices unsupported by evidence such as inappropriate use of antimicrobial dressings. Gray et al (2018) suggested that strategies were needed to identify, assess and disinvest from products and practices supported by little or no evidence and enhance the uptake of those that were (Gray et al, 2018). Both Guest et al (2015) and Gray et al (2018) therefore identified the need for education and training and a consistent approach to care delivery in both local and national settings.

A more recent publication by Guest et al (2020) showed that five years on from the original study (Guest et al, 2015) the NHS was encountering more wounds, rising costs and delivering more

Table 1: The burden of wounds over a five-year period.

	2012/13 ¹	2017/18 ²
Wound prevalence annually	2.2 million	3.8 million
Annual cost	4.5–5.1 million	8.3 million
% of cost incurred in the community	66.3 million	81 million
Total number of community nurse visits (millions)	10.9 million	54.4 million
Total number of practice nurse visits (millions)	18.6 million	28.1 million
Total number of healthcare assistant visits (millions)	Not stated	53.6 million
Guest et al, 2015 ¹ ; Guest et al, 2020 ²		

Rachel Sweeney, tissue viability specialist nurse, Norfolk Community Health and Care Trust, Norfolk



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community-based treatments (Table 1). Furthermore, the community workforce had changed with more healthcare assistants involved in wound care delivery as the highly trained nurse workforce declined. The unwarranted variation in care originally highlighted by Guest et al (2015) was still observed with 25% of wounds lacking a differential diagnosis, and only 15% of patients with a leg or foot ulcer having a Doppler ankle brachial pressure index (ABPI) measurement recorded in their notes. This is in part explained by the recent description of wound care services as having increased time pressures and diminishing resources, which could considerably impede care delivery (Gray et al, 2019).

To deliver a consistently high standard of wound care under these circumstances, the issues of education and training of the community workforce to deliver evidence-based care and eliminate unwarranted variation in practice clearly needs to be addressed on both a local and national level. The National Wound Care Strategy Programme (NWCSP) was launched in 2018 by NHS England and NHS Improvement in order to develop a national strategy that focuses on improving care relating to pressure ulcers, lower limb ulcers and surgical wounds in England (NHS England, 2021). On a local level, services can be developed or redesigned to address the problems highlighted by research.

This paper describes the experience of a community-based tissue viability service (TVS) which was established in 2015 and developed over the same five-year period during which research evidence of issues affecting wound care services nationally were emerging, and highlighted the problems which needed to be addressed nationally to enable efficient wound care delivery (Gray et al, 2018; Guest et al, 2015; 2020). Some of these issues were encountered locally and were considered in the development of the service to ensure that it was fit for purpose into the future.

NORFOLK COMMUNITY HEALTH AND CARE NHS TRUST (NCH&C) TISSUE VIABILITY SERVICE

Norfolk Community Health and Care NHS Trust (NCH&C) currently provides community-based services across Norfolk. The TVS provides complex wound care for a large population of approximately 808,424 patients and is led by two full-time equivalent (FTE) tissue viability nurse specialists (TVNS).

‘While tissue viability roles may vary from trust to trust, they all have in common that they encompass more than the clinical management of complex wounds.’

Background to the tissue viability service

In 2015, the author took on a new TVNS role to establish and develop a service to manage people with complex wounds in the community and on discharge from the acute setting. The new role complimented an existing but unfilled TVNS post, which was subsequently filled by a new clinician within weeks.

The author’s original position, which was commissioned by West Norfolk clinical commissioning group (CCG), is now commissioned by Norfolk and Waveney CCG, which was formed in 2020 from the merger of four CCGs in Norfolk (North Norfolk, Norwich, South Norfolk, and West Norfolk) with Great Yarmouth and Waveney CCG. As a consequence of this historical commissioning, the author’s role continues to provide a TVS to West Norfolk. Currently, in West Norfolk, there are four community nurse bases, seven nursing homes and 12 link nurses. The other TVNS role is commissioned by NCH&C Trust, and together the two nurses lead the TVS. Across Norfolk there are 16 community teams who use the service.

Service development: identifying good practice and areas for improvement

While tissue viability roles may vary from trust to trust, they all have in common that they encompass more than the clinical management of complex wounds (Holloway et al, 2019). The TVNS role also includes support of innovation, strategic development, business planning, and teaching and education. Team management, audit and data analysis and creation of clinical policy and procedure are all essential skills, in addition to collaborating with stakeholders to ensure evidence-based practice is at the heart of service provision (Holloway et al, 2019).

As part of establishing the service in 2015, all aspects of wound care were examined by the TVNS (including procurement, formulary, and clinical practice) and an action plan developed to identify areas of good practice and where improvements could be made. This approach was subsequently recommended in The *Leading Change, Adding Value* framework (NHS England, 2018) in order to drive efficiency and eliminate unwarranted variation in practice within budget (NHS England, 2018).

The TVNS compared existing practices and procedures to best practice and national guidelines at that time to highlight areas where practice needed updating and thus education and training were required. Initial meetings were held with the community nursing teams to enable them to raise any issues, and the TVNS shadowed and observed clinical practice in the community to further pinpoint areas of good practice and those needing improvement. This approach also enabled the building of relationships between the new in-post TVNS and community teams. Clinical audit was performed in line with the trust’s existing audit plan, while policy reviews were undertaken in order of review date, with updates made where required.

These actions are all fundamental to the TVNS role and the ongoing

development of a TVS and continue to be done on an ongoing basis.

Formulary and dressing use review

Community nurses have reported feeling reassured that using a formulary helps them to make correct patient management choices, especially if accompanied by clinical guidelines and pathways, while specialist nurses have reported that using a formulary helps to reduce incorrect product selection and standardises product use across a service (Gray et al, 2019).

The author reviewed the existing tissue viability formulary, which was found to be fit for purpose, with wound dressings available in all of the main dressing categories (e.g. foams, antimicrobials, films, silicones, and superabsorbents). An online non-prescription ordering service (ONPOS; Coloplast) was already in use by the trust to procure wound dressings listed on formulary, with good compliance. Using the service enabled dressings to be ordered from the formulary without the need for a prescription. ONPOS has been available for more than a decade and is currently used by over 80 organisations in the UK. These trusts have reported multiple benefits from using ONPOS, including improved formulary compliance of between >85–100% (Knight, 2010; Grothier, 2013; Griffin, 2015; Markey and Barrett, 2017; Dowley and Tomes, 2018; Warner, 2021).

As part of the partnership commitment to users of ONPOS, Coloplast provides ongoing support which includes the generation of monthly reports that provide real-time data analysis of dressing usage and spend. Monthly data analysis meetings were therefore carried out with the Coloplast territory manager. The real-time data generated by ONPOS allowed patterns in product use and spend to be analysed, and any unexpected trends to be investigated further, such as inappropriate product use, which could then be addressed through local education and training.

For example, in 2017, monthly

ONPOS reports highlighted a large spend on hydrofiber dressings. On further investigation, the dressings were being used as fillers under a secondary wound dressing in deep wounds. This was despite Biatain® Silicone (Coloplast) being listed on the formulary since 2015 and indicated for use on wounds up to

'Other trusts have also reported savings generated from correction of inappropriate product use, initially highlighted by irregular spend on dressings by ONPOS reports.'

2cm deep. Driven by this information, an educational event was held to introduce Biatain Silicone with 3DFit® Technology that emphasised that no filler was needed in wounds up to 2cm deep. This education reinforced the correct use of the formulary dressings, simplified care and led to a reduction in spend on hydrofiber dressings resulting in savings of £25,094 (from a spend of £165,199 between April 2017–18, to £140,105 between April 2020 and March 2021). A large reduction in the number of foam dressings used from 2015 was also observed (Figure 1).

Similarly, Warner (2021) reported that ONPOS data highlighted inappropriate alginate spend on surgical wards in an acute trust. Further investigation revealed that the dressings were being used as

unnecessary cavity fillers in some wounds, incurring unnecessary costs. Warner (2021) also reported that a reduction in the use of cheaper foam dressings that needed frequent changes with more expensive dressings that had a longer wear time resulted in savings. Similarly, more expensive silicone foam dressings were found to prevent the skin stripping on removal that had occurred with a cheaper foam, demonstrating that dressings with a higher unit cost can result in cost savings and improve patient experience (Warner, 2021).

Other trusts have also reported savings generated from correction of inappropriate product use, initially highlighted as irregular spend on dressings in the monthly ONPOS report. Dowley and Tomes (2018) and Jones (2020) reported that ONPOS real-time data highlighted large silver dressing spend in their trusts, which were a consequence of dressing misuse. With education and training on appropriate practice, Jones (2020) reported that silver spend was reduced by £6K per month.

Community healthcare staff

Evaluation of the community workforce identified that healthcare staff responsible for delivering wound care across the trust had differing levels of qualification, knowledge and skills in wound management. Gray et al (2019) reported that clinician respondents to a survey about factors influencing community wound care practice all felt that wound care knowledge across acute, primary

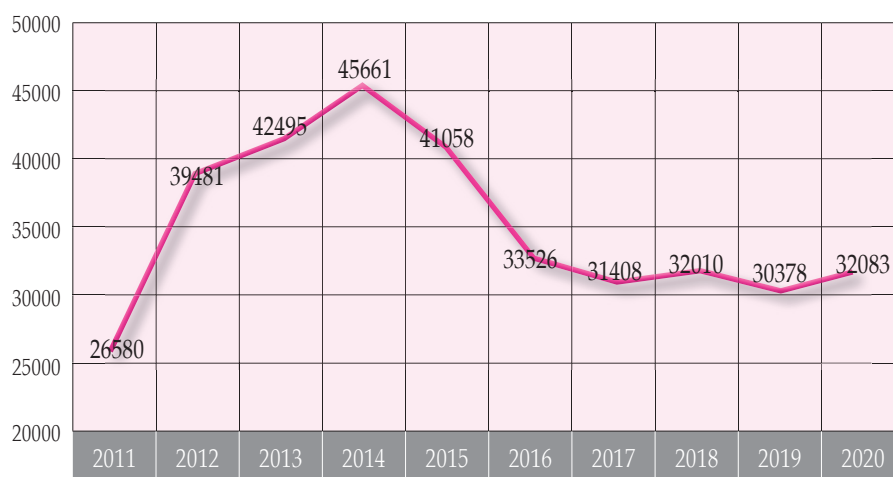


Figure 1. Reduced volume of foam dressings ordered.

care and nursing home services was poor, leading to increased workloads for specialists. As a consequence of the varying wound care knowledge and skills in Norfolk, it was decided to go 'back to basics' and create an educational benchmark for all staff delivering wound care. Currently, approximately 45% of all community nursing teams in Norfolk West are band 3–4, and therefore require ongoing support and skills development.

Delivery of education and training

A key part of the TVNS role is teaching and delivery of education and training, however, with only two TVNS disseminating information across a trust, implementing change can be challenging, if not impossible (Everitt, 2008). One solution is the use of a link nurse group, which consists of members of staff with an interest in tissue viability who attend regular meetings, develop their knowledge and skills, and then cascade information and education on tissue viability back to general staff in their area of work (Everitt, 2008; Renwick, 2020). With only two FTE TVNS for the large patient population of Norfolk, it was decided to take this approach.

Link nurse forum

The first link nurse forum was developed by both TVNS and held at the community hospital, as this was a central location in the county. Both TVNS collaborated to develop joint educational initiatives to provide wound care education relevant to all care settings and knowledge and skill levels to promote evidence-based care delivery. Clinical team leads were asked to nominate a registered nurse and a healthcare assistant to become tissue viability link nurses, with the expectation of recruiting 25–30 link nurses to attend the meetings and disseminate wound care knowledge in their workplace.

The first link nurse meeting was held over half a day in June 2015 in the hospital. It provided a general introduction to the link nurse role and also gave an update of the work being undertaken by the TVNS. Subsequent link nurse meetings

were also held over half a day in the hospital with content determined and delivered by the TVNS. Companies with products on the formulary were also invited to attend relevant events to provide updates when appropriate, enabling the basics underpinning the wound care formulary to be refreshed as required.

'The collaborative working with Coloplast to deliver education allowed a breadth and variety of sessions which otherwise would not have been possible due to limited resource.'

Information on fundamental topics such as wound assessment were delivered at the early meetings, later followed by events based around policies that were being reviewed and published at the time. For example, pressure ulcer policy was overhauled by the TVNS in early 2016, in order to meet both local and national agendas. The trust had implemented the *Stop the Pressure* programme following its development by NHS Midlands and East in 2012 and continued to follow the strategies set by the initiative (www.stopthepressure.co.uk). Education was delivered to run alongside the publication of the pressure ulcer policy. Pressure ulcer workshops facilitated by the TVNS were arranged for staff to book onto and attend. The agenda went through the fundamentals of pressure ulcer development, including categorisation, prevention strategies, supporting documentation and operationalising the new policy. This has been a rolling programme and continues to be implemented.

Initially the TVNS tried to manage the educational events in-house. However, with increasing workloads and declining participants, with anywhere between 2–15 clinicians typically attending, it was recognised that the link nurse meeting format was no longer working. Reduced attendance was largely attributed to over-running caseloads leading to a delay in

arrival or total absence. This was also noted by Gray et al (2019), who stated workforce pressures often led to poor attendance or cancellation of in-house educational events for community practitioners.

Coloplast had previously delivered some well-evaluated education sessions during the link nurse events, so the TVNS decided to build upon this success and develop the working partnership further. The TVNS approached the Coloplast territory manager to discuss options for the link nurse events and Coloplast offered to work in partnership to take a new approach. It was decided to hold a whole link nurse day every quarter, off site, to enable attendees to obtain study leave and protected learning time for the day. The TVNS designed the first agenda, while Coloplast provided administrative support, such as sourcing a venue, managing bookings, and sponsoring the event.

Events and protected learning time

The first TVN link nurse programme was held in partnership with Coloplast in 2018. The programme consisted of live seminar events, presented by Wound Care Connections and Coloplast TVNA. Content was determined by the TVNS in order to mirror current national initiatives such as NWCSF, *Stop the Pressure* and *Legs Matter*, to provide education requested by the link nurses or updates on new policy, pathways, and products on formulary (Table 2). With 'protected learning' time and a more formal approach to education and training, better turnout was achieved, with each event attended by approximately 40 link nurses from across the trust. The events provided excellent opportunities for both the TVNS and link nurses to network and share experiences and ideas, while a variety of speakers with experience of working in other parts of the country offered insight into national agendas. This created a sense of validation when attendees realised that similar challenges were being faced elsewhere and that national initiatives were being developed and implemented to support wound care practice.

Table 2: Link nurse events

2018	CQUIN wound assessment/ <i>Stop the Pressure</i> campaign
May 2019	3D Fit® Technology/skin tears
June 2019	aSSKINg for nursing home/care homes (60)
July 2019	aSSKINg for nursing home/care home (West Norfolk) (65)
Oct 2019	Mock coroner's court documentation
March 2020	CQUIN (leg ulcer and pressure ulcer indicators)
July 2020	(Virtual) – Pressure ulcers/ <i>Stop the Pressure</i> day
November 2020	(Virtual) – Pressure ulcers/ <i>Stop the Pressure</i> day



Figure 2.
Annual total spend.

The collaborative working with Coloplast to deliver education allowed a breadth and variety of sessions which otherwise would not have been possible due to limited resource. The partnership approach significantly relieved pressure on the TVNS, saving time on the administrative tasks associated with organising the events. The time saved enabled the TVNS to deliver further training, including a comprehensive in-house leg ulcer training programme.

HEAL

As the Covid-19 pandemic unfolded in 2020, the events were adapted to be held digitally with good attendance, preventing disruption to education delivery.

In addition to the events, further educational support is available through partnership working. The Healthcare Excellence through Access and Learning (HEAL) educational initiative from Coloplast enables staff to access educational materials, including local policies and guidelines, as

well as national guidelines and a library of wound literature through ONPOS via 'non-ordering access'. The availability of a platform for staff to access educational and training materials for different levels of knowledge means that best practice recommendations and resources are readily available to inform practice.

The HEAL programme includes a number of medical educational courses that cover a variety of wound care topics. Each course has been developed in close collaboration with international wound care experts, and the content is peer-reviewed and endorsed by the European Wound Management Association (EWMA).

COST SAVINGS

Analysis of data relating to product spend and usage has enabled areas of potential inappropriate practice to be identified and education and training delivered to improve it. Consequently, there has been a decrease in product spend over a five-year period (*Figure 2*), against a prediction of year-on-year increasing

costs (Guest et al, 2017). Similar savings have also been reported by numerous other community trusts using ONPOS for dressing procurement (Grothier, 2013; Griffin, 2015; Markey and Barrett, 2017; Dowley and Tomes, 2018; Jones, 2019).

DISCUSSION

A new TVS was established in 2015 to service a large population of people with complex wounds in a community setting. The service was led by two FTE TVNS and so collaborative working was needed to ensure the TVS was in alignment with national and trust agendas to deliver a high standard of wound care to patients with limited resources.

The TVNS reviewed the approach to wound care delivery and made improvements to align with trust values and national agendas to deliver high quality, evidence-based care. Key to this was the ongoing review of clinical practice and delivery of education and training. The workforce had varying levels of skill, and since the development of the TVS to the present day, staff demographics have changed in accordance with the changes noted by Guest et al (2020) that more HCAs are delivering care — 45% of wound care is delivered in West Norfolk by grade 3–4 healthcare assistants. This presents a challenge to TVNS to deliver ongoing education and training.

Establishing a link nurse network greatly helped with the delivery of education and training, and partnership working with Coloplast helped the TVNS to role out a comprehensive and relevant educational programme that was relevant to address both local and national issues. Working in collaboration helped to free up further time to provide more education where needed. Taking an adaptable approach to service delivery is essential, and more recently, virtual education events have been used so that the Covid epidemic did not significantly impact on the learning of clinicians still delivering wound care.

Remember...

When making a decision about which dressing to use, the cheapest dressing is not necessarily the most cost-effective. It may need more frequent changes, incurring costs associated with the number of dressings and nursing time needed.

However, provision of education does not guarantee translation into practice. Fortunately, benefits of the approaches taken were observed; documentation standards improved and more detail was recorded in patients records, and lateral thinking became evident. Clinical principles discussed in some of the sessions, e.g. cavity wound management, were seen to support clinical decision-making with regards to dressing plans and improved use of terminology in patient records.

The successful use of data collection and analysis to inform change was demonstrated through the use of ONPOS. Access to real-time data on dressing use and spend allowed areas of unwarranted variation to be identified, and education delivered on appropriate use, leading to savings on dressing expenditure. Similar outcomes have been reported in other community settings where ONPOS is in use (Grothier, 2013; Griffin, 2015; Markey and Barrett, 2017; Dowley and Tomes, 2018). In Norfolk, wound dressing spend decreased year on year, despite costs increasing year on year nationally (Guest et al, 2020).

The next step would be for the TVS to collect data to measure the impact of education delivery on practice.

CONCLUSION

This article describes how a community TVS developed over a five-year period, taking a proactive rather than reactive approach to service improvement. Through regular and consistent review of practice, including dressing use through real-time data analysis, areas for improvement were identified and

education and training delivered to improve care delivery.

Key to the success of developing the service was working in collaboration with link nurses and industry to deliver evidence-based wound care education to upskill the community workforce. **JCN**

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Family and other unpaid carers supporting people with dementia

Zena Aldridge, Karen Harrison Dening

As the population continues to age and the incidence of dementia and associated costs increases, there will be a greater need for unpaid care with research suggesting that one in three of us will become a carer for someone with dementia during our lifetime. It is estimated that there are in excess of 700,000 people in the UK acting as primary unpaid carers for people living with dementia, all of whom make a substantial contribution to their care and support. Carers of people living with dementia can experience high levels of carer burden alongside poor health and wellbeing because of their caring roles. However, they may not identify themselves as carers or be recognised as such by health and social care professionals. Consequently, they may not have access to the support they need, thus identifying and valuing unpaid carers is the first step in supporting them. Community nurses are well placed to do this. This sixth paper relating to dementia considers the contribution of unpaid carers in the context of the families of Dhriti Singh and Gregory Brewin, who we have been following throughout this series.

KEYWORDS:

■ Dementia ■ Unpaid carers ■ Information ■ Support

Wittenberg et al (2019) estimated that by 2020 there would be approximately 907,900 people living with dementia in the UK at a cost of £36.7 billion to the country's economy. A breakdown of these costs attributed 14% of the total cost to health care, 45% to social care, 1% as other costs, but a staggering 40% as a result of unpaid care (Wittenberg et al, 2019). Lewis et al (2014) estimated that there are in excess of 700,000 unpaid carers supporting people with dementia and went on to suggest that if the ratio of unpaid carers to people with dementia was to remain

'It has also been estimated that due to the rising numbers of people living with dementia, one in three people will provide unpaid care for a person with dementia during their lifetime.'

the same, this number would need to increase to 1.7 million by 2050. It has also been estimated that due to the rising numbers of people living with dementia, one in three people will provide unpaid care for a person with dementia during their lifetime (Newbronner et al, 2013).

Dementia strategies of many developed countries propose that supporting people with dementia to live at home for as long as possible is a priority (Colombo et al, 2011). Remaining at home is recognised

as being not only vital to reduce statutory care costs, but also to improve quality of life for people with dementia (Muir et al, 2015). As a consequence of this drive to care for people in the community, there is an increasing need and role for unpaid carers.

A survey of adult carers in England 2016–2017 identified that 30% of unpaid carers had been caring for someone with dementia for between five and 10 years, with 22% doing so in excess of 10 years (Alzheimer's Research UK [ARUK], 2021; NHS Digital, 2017). The same survey found that 36% of these unpaid carers spend more than 100 hours caring for a person with dementia, and that 63% were retired, with a further 18% in work and 15% stating that they are not in work due to their caring responsibilities (ARUK, 2021; NHS Digital, 2017).

Newbronner et al (2013) found that the majority of unpaid carers of people with dementia were in their 50s and 60s, trying to balance work and caring for parents, or were older people caring for partners. However, unpaid carers can have various relationships with the person with dementia, such as adult child, grandchild, spouse, etc, although relationships are not always confined to familial ones. The Carers Trust (2021) define a carer as anyone who cares, unpaid, for a friend or family member who, due to illness, disability, a mental health problem or an addiction, cannot cope without their support.

Many people do not identify themselves as a carer, instead seeing gradually increasing care-related activities and responsibilities as part of an ongoing relationship with the person with dementia, not as

Zena Aldridge, Admiral Nurse research fellow, Dementia UK, PhD student, De Montfort University, Leicester; Karen Harrison Dening, head of research & publications, Dementia UK and professor of dementia nursing, De Montfort University, Leicester

a separate or new role (Carduff et al, 2014; Aldridge, 2019). Rand et al (2019) suggest that people who choose to be carers have a better quality of life and less carer strain than those who feel that they are expected to care.

IMPACT OF CARING

While those carers who choose to care have a better quality of life and experience less carer strain, delivering care to a person with dementia can be multifaceted and complex. Caring often encroaches on all aspects of a carer's life, which can result in social isolation in addition to mental, physical and financial stressors (Brodaty and Donkin, 2009; Lindeza et al, 2020). It has been suggested that caring for someone with dementia differs from caring for people with other illnesses and disabilities due not only to the complexity of dementia, but also because of its progressive and unpredictable nature (Newbronner et al, 2013).

The additional negative consequences of caring for someone with dementia may be in part be due to the emotional impact of the role, which can leave carers of people with dementia experiencing feelings of guilt, anger, resentment, sadness and grief (Lindeza et al, 2020). Brodaty and Donkin (2009) state care burden in dementia care is a consequence of additional and multiple factors, including:

- ▶ The high level of support that is required
- ▶ Dealing with other life events
- ▶ Managing the behavioural and psychological symptoms of dementia
- ▶ Family conflict
- ▶ Social isolation
- ▶ Fatigue and burnout
- ▶ The impact on relationships
- ▶ The physical and mental capacity of the person to be a carer.

Carers often feel ill equipped to manage the complex needs of the person they care for and assume the role with little or no understanding of dementia and its effects on both themselves and the person for whom they care (Brodaty and Donkin, 2009).

All too often, people with dementia, their families and carers receive little or no support following the diagnosis and fall through the cracks that exist within health

'... despite the challenges and demands experienced by unpaid carers of people with dementia, many find their caring role a rewarding experience, which can strengthen their emotional bonds and relationships.'

and social care systems due to the fragmentation of service provision and gaps in care for families affected by dementia (Martin et al, 2018; Aldridge 2019). Furthermore, there are a significant number of people who have not received a formal diagnosis of dementia; this can impact upon the ability to identify those with caring responsibilities and so restricts their access to appropriate services. It is therefore essential for generalist professionals not only

to be aware of potential symptoms of dementia and encourage further assessment, but also to identify the needs of family carers and support required (see Harrison Denning and Aldridge, 2021a).

It is important to acknowledge that, should a person with symptoms of dementia decline assessment, this does not preclude the family's and carer's needs to access appropriate information and support in their own right. They will still be trying to adjust and cope with the changes in the person they care for and have concerns about what this means to their own lifestyle and future plans (Aldridge, 2019). However, despite the challenges and demands experienced by unpaid carers of people with dementia, many find their caring role a rewarding experience, which can strengthen their emotional bonds and relationships (ARUK, 2015; Aldridge 2019).

IDENTIFYING CARERS

There may be several unpaid carers providing support to one person

Dhriti Singh is a 59-year-old woman who has lived with a diagnosis of vascular dementia for the past six years. She also has heart failure and hypertension and a longstanding problem with urinary continence and over recent months has developed intermittent faecal incontinence. Until recently, her husband, Arjun, has been her main carer, sharing his wife's care with a paid carer who visits their home three times a day across the entire week to provide personal care to Dhriti.

Patient story one

As Dhriti's needs increase, Arjun has been struggling to cope and, as a result, has become increasingly stressed and depressed but he does not want Dhriti to be moved to a care home. Following a family discussion, it was decided that the time had come for their three children to provide increased support to their parents. Their eldest daughter, Atara, is expecting her first child and is working full time but for the past four months has stayed at her parents' house over the weekends and prepares meals for the coming week, which has put a significant strain on her relationship with her husband. Advik, their son, is soon to be married and travels a lot for work, but is providing financial support to his parents and visits as much as he can. It was decided that their youngest daughter, Prisha, would move into the family home and give up her job as a nurse to care for her mother, who is now approaching the end stages of dementia, with support from an ongoing package of care.

Patient story two

with dementia. Similarly, some family members and carers may be supporting several people with dementia. Unpaid carers can often be hidden from the attention of health and social care services, but all will have their own needs. Burns states in the Dementia Action Alliance’s *Carers Call to Action* (2014) that when a diagnosis of dementia is given, it is not just to one person, but also to a spouse, partner, child, extended family and friends. Thus, it is important to recognise that every time a diagnosis is made, it is life changing for many. This paper will now consider the needs of family carers in practice through the lens of two ongoing case studies. Previous articles in this series have followed the stories of Dhriti Singh and Gregory Brewin (Aldridge and Harrison Denning, 2021a; Aldridge and Harrison Denning, 2021b; Harrison Denning and Aldridge, 2021a; Harrison Denning and Aldridge, 2021b; Harrison Denning and Aldridge, 2021c).

PATIENT STORY ONE: DHRITI SINGH

Until recently, it had appeared that Arjun was the sole unpaid carer, but there are now multiple unpaid carers within this family offering varying levels of support and care. However, they may not accept or recognise their caring roles as anything out of the ordinary and could have different perspectives of the changes in their roles and responsibilities based upon their cultural beliefs and values. There is evidence to suggest that children from South Asian families see caring for parents as a duty in reciprocity of the care they received from their parents as children and young adults. South

Gregory Brewin has a mixed diagnosis of Alzheimer’s and vascular dementia. He has managed to continue to live alone for several years supported by community and primary care services who have monitored his comorbid conditions of diabetes and chronic obstructive pulmonary disease (COPD). He has a package of care with a paid carer visiting twice a day, seven days a week. Gregory has been experiencing increased confusion and anxiety over the past few months, which has led to him leaving the house at night and knocking on his neighbour, Brenda’s, door. Initially, this was a rare occurrence, but is now becoming more frequent. Gregory’s family do not live locally and both sons, James and Ian, live and work in London and visit on ‘high days and holidays’. However, because of their dad’s declining health, they now try and visit alternate weekends.

James and Ian both hold Lasting Power of Attorney and have been managing their dad’s finances and affairs for a couple of years and liaise with health and social care services in relation to his package of care. In between visits, they try and keep in contact with Gregory by phone, but he does not always answer so they have become increasingly reliant on Brenda to keep an eye on him and be the point of contact. Both sons are struggling to balance their work and family commitments. Although they are visiting more frequently, they are concerned about their Dad’s safety as he continues to live alone. Brenda has always been happy to help, but is finding the increased nightly disturbances and responsibility of keeping an eye on Gregory difficult, as she has her own health problems.

‘It should also not be assumed that the provision of care within the wider family is an indication that members of the family do not require care and support with their caring roles. Such blanket assumptions can lead to unpaid family carers not being offered the services they need.’

Asian families are often reluctant for the person with dementia to move to a care home, even in the later stages as dementia advances (Herat-Gunaratne et al, 2020). Cooper et al (2010) found that people from ethnic minority groups are more likely to care for family members with less formal care compared with white majority populations. However, this should not be seen as an indication that unpaid family carers from South Asian cultures do not experience negative effects of caring. On the contrary, it has been suggested

that South Asian carers may in fact experience higher levels of burden, anxiety and depression than British white counterparts, which may be a consequence of the perceived cultural stigma of dementia, racism, and being perceived as a migrant, lower socio-economic status and inequality (Parveen and Oyeboode, 2018).

It should also not be assumed that the provision of care within the wider family is an indication that members of the family do not require care and support with their caring roles. Such blanket assumptions can lead to unpaid family carers not being offered the services they need (Parveen et al, 2017).

In the case of Dhriti’s family, there is already clear evidence of strained relationships, financial burden and changing roles. This comes at a time when they are also trying to come to terms with the fact that Dhriti is likely to be approaching the end of her life while there are forthcoming significant life events in the family, including the arrival of a first

Reflective points

Consider each family member in this case: Arjun, Atara, Advik and Prisha and how their caring roles and other stressors might be impacting upon each of them? What information, services and resources might support their individual needs?

Reflective points

Reflecting upon cases you have on your caseload, are you able to identify any family and or other unpaid carers of people with dementia who may need support?

Do you know what resources are available to support informal family and unpaid carers of people with dementia in your area?

grandchild and a wedding, all of which may affect their health and wellbeing.

PATIENT STORY TWO: GREGORY BREWIN

Often when people with dementia live alone it may be thought that there are no unpaid or family carers available to support them. However, there may be 'non-kin' carers, such as friends or neighbours (Pleschberger et al, 2019), or family members caring from a distance (Carers UK, 2011).

This is the case with Gregory, as both his neighbour, Brenda, and his two sons have caring roles, which may be less obvious to local health and social care providers. There is evidence to suggest that family members caring from a distance are often of the 'sandwich generation'; trying to care for children and parents simultaneously, which can cause issues with employment as they try to juggle responsibilities causing increased stress and anxiety (Carers UK, 2011). Some of the difficulties faced because of caring from a distance include:

- ▶ Feeling guilty about not being able to do enough
- ▶ A detrimental impact on finances due to having to take time off work and engage in expensive travel
- ▶ Finding time to juggle all the responsibilities (Carers UK, 2011).

All of which can have a negative impact on their physical and mental wellbeing.

Similarly, Brenda may not be

identified as a carer. However, without her support, it is unlikely that Gregory would have been able to stay in his own home until this point. The potential impact of the support she is offering to Gregory and his sons is significant, but she may not be able to sustain it for much longer which could have significant implications for Gregory and his ability to remain in his own home. Identifying Brenda as a carer and a key partner in Gregory's care is important, as is the need to consider Brenda's own needs as well as determining her willingness to continue in her caring role.

WHAT SUPPORT DO CARERS WANT AND NEED?

Although there are different ways in which carers wish to access support, consistent themes do emerge within the literature which indicate what they consider to be helpful. For many informal and family carers, communication and information about dementia and its effects are vital to improve their knowledge, and to help them develop coping strategies and acquire skills to strike a balance between their own needs and those of the person for whom they are caring (Bressan et al, 2020). Furthermore, it is well documented that carers need access to appropriate, individualised support to meet their own social, health, psychological and emotional needs (Brodaty and Donkin, 2009; Bressan et al, 2020).

Given the heterogeneity of carers and the variance in the support they provide, there is no ubiquitous, 'one size fits all' approach to offering support. However, in the authors' experience, enabling people to acknowledge their caring role and own needs is the first critical step in assisting them to access support they may need.

CONCLUSION

Whether or not a person chooses to identify themselves as a carer is not the priority. Of greater importance is that health and social care professionals recognise the contribution that unpaid carers

make to supporting and caring for people with dementia and see them as legitimate partners in care. Each person will have their own experiences, beliefs, values and expectations about their caring role, which requires a bespoke approach to identifying and meeting their individual needs.

Valuing the family and unpaid carer role and enabling access to information and support, which not only supports them to look after the person with dementia but, as importantly, to look after themselves, is a positive first step in ameliorating some of the detrimental effects of caring for someone with dementia. This is something that community nurses are well placed to do within their roles. **JCN**

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Useful resources

- ▶ Dementia UK Admiral Nurse Helpline: 0800 888 6678
- ▶ Alzheimer's Society National Dementia Helpline: 0300 222 1122
- ▶ Age UK Advice Line: 0800 055 6112
- ▶ Independent Age: 0800 319 6789
- ▶ Carers Direct Helpline: 0300 123 1053
- ▶ Carers UK: 0800 808 7777
- ▶ TIDE (Together in dementia everyday): www.tide.uk.net/

KEY POINTS

- As the population continues to age and the incidence of dementia and associated costs increases, there will be a greater need for unpaid care with research suggesting that one in three of us will become a carer for someone with dementia during our lifetime.
- Dementia strategies of many developed countries propose that supporting people with dementia to live at home for as long as possible is a priority.
- Unpaid carers can have various relationships with the person with dementia, such as adult child, grandchild, spouse, etc, although relationships are not always confined to familial ones.
- Caring often encroaches on all aspects of a carer's life, which can result in social isolation in addition to mental, physical and financial stressors.
- Unpaid carers can often be hidden from the attention of health and social care services, but all will have their own needs..
- Valuing the family and unpaid carer role and enabling access to information and support, which not only supports them to look after the person with dementia but, as importantly, to look after themselves, is a positive first step in ameliorating some of the detrimental effects of caring for someone with dementia.

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What community nurses should know about gastrointestinal disorders

Margaret Perry

Gastrointestinal disorders cover a wide spectrum of diseases which differ widely in their signs and symptoms, severity, treatment options and long-term prognosis, as well as their impact on the quality of life of those affected. They can affect any part of the gastrointestinal tract and many can occur at any age, although as with other conditions, some are more prevalent in specific age groups. This article focuses on only three of the many diseases which fall into this category to give community nurses and non-medical prescribers a brief insight into their recognition, management and treatment, with the aim of increasing confidence and knowledge of the diseases discussed.

KEYWORDS:

■ Diverticular disease ■ Crohn's disease ■ Ulcerative colitis

Gastrointestinal conditions can affect anyone and vary widely in their presentation, disease course, and impact on the health and wellbeing of those affected. This article focuses on three conditions to give community nurses and non-medical prescribers more knowledge and confidence in assessing and advising patients affected by one of the diseases discussed.

The conditions covered include:

- ▶ Diverticular disease
- ▶ Crohn's disease
- ▶ Ulcerative colitis.

DIVERTICULAR DISEASE

Diverticular disease occurs when there is the development of a sac-like protrusion in the muscular wall of the colon. The condition may occur as (Knott, 2020):

- ▶ Diverticulosis: diverticular are present but the patient is asymptomatic
- ▶ Diverticular disease: the patient has symptoms associated with the diverticular but these may settle without treatment (see below)
- ▶ Diverticulitis: this relates to those who experience more severe symptoms (tachycardia, fever) with or without the addition of features such as abdominal pain and malaise. Of those who fall into this category, approximately 75% will have at least one episode of diverticulitis after diagnosis.

Prevalence

Prevalence increases in older adults, with diverticulosis present in 5–10% of those aged 45 years or older, increasing to 80% in adults aged 80 or older, but rare in those below the age of 40 (National Institute for Health and Care Excellence [NICE], 2021). Diverticula are usually multiple and occur in the sigmoid colon in 85% of people and the remaining 15% are found in the right colon (more common in people of Asian origin) (NICE, 2021).

Risk factors include (Knott, 2020; Mayo Foundation for Medical Education and Research, 2021a):

- ▶ Age — about half of all people in the UK have diverticula by the time they are 50 years old, increasing to nearly seven in 10 by the age of 80 years of age
- ▶ Obesity — being seriously overweight increases risk
- ▶ Smoking — diverticulitis is more commonly seen in cigarette smokers than non-smokers
- ▶ Lack of exercise — vigorous exercise appears to lower the risk of diverticulitis
- ▶ High fat, low fibre diet — a low-fibre diet in combination with a high intake of animal fat seems to increase risk, although the role of low fibre alone is not clear
- ▶ Certain medications — several drugs are associated with an increased risk of diverticulitis, including steroids, opioids and non-steroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen and naproxen.

Pathophysiology

A diverticulum is a mucosal protrusion through the intestinal wall that occurs along natural areas of weakness (Ghoulam, 2019). These small herniations extend into the peritoneum and for many cause no problems and may go undetected (diverticulosis). They occur most commonly in the left colon, although they may be found anywhere in the large, or (more rarely) small intestines (Ohio State University, 2017).

Signs and symptoms

These differ in severity and are dependent on whether inflammation or infection are present. Symptomatic diverticular disease is characterised by non-

specific attacks of abdominal pain, typically colicky in nature, which is often relieved by having a bowel movement (Salzman and Lillie, 2005).

Symptoms are similar to those seen in irritable bowel syndrome (IBS), but patients' age may be useful in helping to make the diagnosis, as IBS is most prevalent in the 20–30 age group (NICE, 2021a), while diverticular disease is more common in older adults (Ghoulam, 2019).

Symptoms of diverticulitis tend to be more severe and are characterised by acute, constant abdominal pain most often occurring in the left lower quadrant (Salzman and Lillie, 2005). With the development of infection and inflammation, patients will experience more severe and constant pain, become feverish and may also develop nausea and vomiting with constipation or diarrhoea (NICE, 2021a).

Diagnosis

For those whose condition remains asymptomatic, a confirmed diagnosis may never be made, or the disease may be found opportunistically. However, in the presence of symptoms, the patient may be referred for a colonoscopy or a computed tomography (CT) scan for further investigation.

Table 1: Patients who may need hospital admission (NICE, 2021a)

▶ Frail and/or elderly, or those who have little support at home
▶ Patients with comorbidities, such as malignancy, diabetes, severe chronic kidney disease (CKD), cirrhosis, or those on immunosuppressive drugs
▶ Patients with symptoms such as severe abdominal pain, which is difficult to manage at home
▶ Patients with complications such as bowel perforation, abscess, rectal bleeding or peritonitis
▶ Dehydration or being at risk of dehydration, as struggling to tolerate fluids at home
▶ Patients who are unable to take or tolerate antibiotics at home if these are needed

Treatment and management

In patients with asymptomatic disease, avoidance of progression to diverticulitis is key. Dietary advice should include emphasis on increasing fibre intake and ensuring adequate fluid intake. Fibre intake should be increased gradually up to approximately 30g daily, which if done over the course of a few weeks will reduce the risk of bloating and excess wind (NHS, 2020), which can be unpleasant. When the patient presents with signs and symptoms of diverticulitis, admission to hospital may be needed (*Table 1*), or it may be possible to treat the patient at home. The severity of the patient's symptoms and their health status, as well as their ability to tolerate fluids, will determine suitability to be treated in the home environment.

Where home treatment is appropriate, this should include (Knott, 2020):

- ▶ Patient monitoring of symptoms and advice to seek medical help if these are not settling or are worsening
- ▶ Antibiotics may be needed for patients who are systemically unwell, are immunosuppressed or those with comorbidities (see *Table 2* for antibiotic choices)
- ▶ Analgesia: paracetamol is recommended
- ▶ NSAIDs, e.g. ibuprofen and opioids — codeine should be avoided as there is a potential risk of diverticular perforation (NICE, 2021a)
- ▶ Clear liquids — these should only be advised initially, with gradual reintroduction of solid food over the next 2–3 days as symptoms improve.

Complications

Unfortunately, complications are likely to be more severe in certain groups of patients. Those who are immunocompromised, organ transplant recipients and those on long-term corticosteroids are considered to be at greater risk (Ghoulam, 2019). A small percentage of patients (4–10%) have ongoing diverticulitis (pain with increased white blood cell counts or raised markers of inflammation, fever,

Red Flags

- Diverticulosis may remain asymptomatic and never be diagnosed
- Prevalence increases with age
- Rare below the age of 40
- Acute diverticulitis may be treated at home, or severe cases may require hospital admission.

and evidence of inflammation found on CT scanning) despite antibiotic treatment, or recurrence of symptoms on completion of antibiotics (Strate et al, 2019).

The commonest complications are (Ghoulam, 2019):

- ▶ Abscesses (the most common)
- ▶ Perforation, obstruction or an intestinal fistula
- ▶ Peritonitis
- ▶ Stricture
- ▶ Sepsis.

Prognosis

The prognosis is highly variable and will be influenced by the severity of the patient's illness and the presence of comorbid diseases or complications. The majority of people remain symptom-free after an initial episode of acute diverticulitis. However, if recurrence occurs, 50% of cases will be within one year of the initial episode and 90% within five years (NICE, 2021a). In rare cases, surgery to excise the diseased part of the bowel is needed when serious complications have occurred and may lead to a temporary or permanent colostomy. However, surgery does not completely eliminate the risk of further problems and one study has reported that the risk of recurrence and abdominal complaints is high (Andeweg et al, 2008). This is more commonly seen among younger patients who experience persistent postoperative symptoms (Andeweg et al, 2008).

CROHN'S DISEASE

Crohn's disease is a chronic relapsing and remitting, non-infectious disease of the gastrointestinal tract. (NICE, 2020a), which can potentially affect patients

at any age. Anyone unfortunate enough to develop the condition will have asymptomatic periods with disease remission, interspersed with unpredictable flares where symptoms become troublesome. Crohn's can start at any age, but usually appears for the first time between the ages of 10 and 40, although there is a small peak in diagnosis in those aged 60 or older (Crohn's and Colitis UK, 2021).

Prevalence

True prevalence rates are not known, but incidence is thought to be

increasing around the world. It is estimated that Crohn's disease affects about one in every 650 people in the UK (Crohn's and Colitis UK, 2021).

Risk factors

No definite cause has been identified, but research has suggested a number of factors may increase risk. These include (Mayo Foundation for Education and Research, 2021b):

- ▶ Age: symptom onset and diagnosis is commonest below the age of thirty
- ▶ Family history: risk is increased in those with a first-degree relative

Red Flags

- Crohn's disease is more common in those aged 15–30 years of age
- Increasing in prevalence in children
- Relapsing and remitting condition
- Use of NSAIDs may worsen symptoms
- Poorest prognosis seen in those with severe symptoms at diagnosis and in younger people at disease onset.

Table 2: Antibiotics for diverticulitis (NICE, 2021a)

Drug	Duration	Additional information	Adverse effects
Co-amoxiclav	Five days	Unsuitable if allergic to penicillin. Use with caution in patients with hepatic impairment, acute lymphocytic leukaemia, chronic lymphocytic leukaemia, cytomegalovirus, higher risk of erythematous rashes and CKD. Reduce the dose if estimated glomerular filtration rate [eGFR] is less than 30	Nausea, vomiting, rashes, diarrhoea
Cefalexin with metronidazole	Five days	Caution needed when prescribing cefalexin if the patient is allergic to penicillin or any other beta lactam: up to 6.5% of patients will also be allergic to cephalosporins	Cefalexin may cause diarrhoea (commonest adverse effect), nausea, vomiting, rashes, headaches, dizziness. Metronidazole, as well as those listed for cefalexin, can also cause myalgia, pruritis, taste disturbance and dark urine
Trimethoprim with metronidazole	Five days	Suitable for those allergic to penicillin. Trimethoprim should not be used for patients with severe liver dysfunction, renal insufficiency or megaloblastic anaemia	Trimethoprim can cause blood disorders (hyperkalaemia, leucopenia, thrombocytopenia, megaloblastic anaemia, rashes and pruritis, nausea and vomiting). Metronidazole adverse effects as listed above
Ciprofloxacin with metronidazole	Five days	Suitable for those allergic to penicillin. Should not be used in those with a history of tendon disorders related to previous quinolone use. Should not be used in those taking corticosteroids as may induce tendonitis and tendon rupture. Caution needed when prescribing for: <ul style="list-style-type: none"> ▶ Diabetics (may raise blood glucose levels). Known cardiac diseases (heart failure, myocardial infarction [MI], or bradycardia) ▶ Epilepsy and those either at risk of seizures or on medication linked to increased seizure risk ▶ Aortic aneurism and/or aortic dissection ▶ Family history of aneurism disease or those with risk factors or conditions increasing the risk of its development 	Can cause, nausea, diarrhoea, dyspepsia, flatulence, headaches, dizziness, sleep problems. Metronidazole adverse effects as listed above

affected by the disease. Statistics indicate that as many as one in five people with Crohn's have a close family member with the disease

- ▶ Ethnicity: more common in white people
- ▶ Cigarette smoking is associated with more severe disease and more likely to require surgery
- ▶ Non-steroidal medications (NSAIDs), such as ibuprofen, naproxen and others do not cause Crohn's, but can lead to inflammation of the bowel, making the disease worse.

Pathophysiology

Crohn's disease begins as inflammation in the intestinal submucosa and crosses the intestinal wall to involve the mucosa and serosa (Ohio State University, 2021). At disease onset, there is inflammation and the development of abscesses and tiny aphthoid ulcers, which may develop into deep longitudinal and transverse ulcers with intervening mucosal oedema, creating a characteristic cobblestoned appearance to the bowel (Walfish and Ching Companioli, 2020a). Further spread of inflammation can lead to thickening of the bowel wall and lymphoedema and, if extensive, can cause hypertrophy of the muscularis mucosae, fibrosis, and stricture formation, potentially leading to bowel obstruction (Walfish and Ching Companioli, 2020a).

Signs and symptoms

Patients often present initially with diarrhoea and abdominal pain as well as additional symptoms which

may include one or more of the following (Ghazi, 2019):

- ▶ Nausea and vomiting
- ▶ Fever
- ▶ Fatigue
- ▶ Rectal bleeding
- ▶ Anorexia
- ▶ Weight loss
- ▶ Younger people may have delayed puberty and developmental delay (the latter may precede gastrointestinal symptoms by years).

Diagnosis

If Crohn's disease is suspected, confirmation is done in secondary care. If the patient is well enough to remain at home while awaiting an appointment, urgent referral to a gastroenterologist is advised. Those who are systemically unwell should be admitted to hospital. Further investigations will be needed before starting treatment (Table 3).

Treatment and management

Treatment aims to control symptoms, reduce the risk of flare ups and whenever possible achieve a sustainable remission, which will ultimately improve patient quality of life. There are several drug treatments available and choice will be based on whether remission of the disease is the key aim, or maintenance once remission has been achieved. More information on drug options is shown in Table 4.

Surgical treatment

Surgery may be needed if drug treatment is ineffective, or for those who develop complications such as perianal disease, fistulas or abscesses. Surgery may be preferred by some patients who wish to avoid long-term medication and is most useful when the disease is confined to the distal ileum (Windsor, 2002). Prophylactic drugs should be considered once surgery has been completed to help prevent postoperative recurrence (Veauthier and Hornecker, 2018).

Complications

Complications are more likely in those who experience more severe or more frequent flare ups of their disease (Walfish and Ching Compañioli, 2020a). These can include:

- ▶ Perforation: a hole develops in the wall of the bowel allowing leakage

Table 3: Specialist investigations to confirm Crohn's disease (NICE, 2000a)

Investigation	Additional information
Colonoscopy	Allows for multiple biopsy specimens which can determine disease extent and severity
Computed tomography (CT scan)	Useful to stage the disease and look for complications, such as abscesses and fistulas
Abdominal ultrasound	Can assess bowel thickness and dilatation (suggesting obstruction) and can also show abscesses, fistulas and strictures
Magnetic resonance imaging (MRI) scan	MRI of the pelvis will determine the extent and location of abscesses and fixture
Abdominal X-rays	Plain abdominal X-rays are used to identify dilatation of the small bowel or colon, which may indicate obstruction

Table 4: Drugs used to treat Crohn's disease (Jarvis, 2019)

Rationale	Medication	Additional information
Monotherapy	Prednisolone Methylprednisolone Budesonide Azathioprine, methotrexate and mercaptopurine Aminosalicylates (e.g. sulfasalazine and mesalazine)	Used to induce remission. Dose is reduced gradually once symptoms settle These drugs are used in more severe cases where steroids have been ineffective or may be added to steroids if the patient has had two or more exacerbations in a 12-month period Can be considered at first presentation or if steroids not tolerated, or ineffective or if there has been an exacerbation in a 12-month period
Add-on therapy	May be needed if there are two or more inflammatory exacerbations in a 12-month period, or the corticosteroid dose cannot be reduced	Azathioprine or mercaptopurine (unlicensed) can be added to a corticosteroid or budesonide to induce remission. In patients who cannot either of these, methotrexate can be added to a corticosteroid
Maintenance therapy	Azathioprine or mercaptopurine Methotrexate	Can be used to maintain remission when previously used with a corticosteroid to induce remission. They may also be used in patients who have not previously received these drugs (particularly those with adverse prognostic factors such as early age of onset, perianal disease, corticosteroid use at presentation, and severe presentations). Methotrexate can be used to maintain remission but only in patients who required this medication to induce remission, or who are intolerant of or are not suitable for the other options

of contents of the gut causing infection or abscesses, which can be potentially life threatening

- ▶ Strictures: narrowing of the gut occurs as a result of scar tissue and inflammation, leading to obstruction
- ▶ Fistulas: these can occur at various sites as a result of inflammation causing a channel to form between two sites of the body. A perianal fistula can also develop, where the channel goes from the anus or rectum and opens on the skin near the anus
- ▶ Cancer: there is a small increase in risk of cancer of the colon in those with Crohn's disease
- ▶ Osteoporosis: poor absorption of dietary nutrients in severe Crohn's

disease can increase the risk of this condition developing.

Prognosis

Prognosis is variable but a poorer prognosis is generally seen in those whose symptoms started at a young age and patients who experienced severe symptoms at presentation, or those with a complicated disease course (NICE, 2020a). While approximately 30% of those affected will have a fairly indolent disease, 50% will require surgery within ten years of diagnosis (Jarvis, 2019).

ULCERATIVE COLITIS

Ulcerative colitis is a form of inflammatory bowel disease

characterised by diffuse inflammation of the colonic mucosa, affecting the rectum and extending along a variable length of the colon (Collins and Rhodes 2006). It is similar to Crohn's disease in that it takes a relapsing and remitting course.

Prevalence

The true prevalence is unknown due to differences in diagnostic criteria used in studies. However, it is thought to be the most common inflammatory bowel disease, affecting men and women equally. Although it can develop at any age, it is most frequently diagnosed in those aged 15 to 25 years (NHS Inform, 2021).

Risk factors

The cause of ulcerative colitis is unclear, but several factors are thought to be linked to disease onset. In healthy people, bacteria, viruses and fungi which reside in the gut (microbiome) serve to aid digestion. Ulcerative colitis is thought to be an immune-mediated condition associated with chronic inflammation and impaired epithelial barrier function caused by triggers such as a change to the normal biome (NICE, 2020b). Genetics appear to have an association, with 10–20% of those affected having at least one family member with either ulcerative colitis or Crohn's disease (Collins and Rhodes, 2006), and greatest risk among first-degree relatives (NICE, 2020b). Smoking seems to give a protective effect, although the reasoning behind this is unclear (Basson, 2019). Use of NSAIDs has also been found to be associated with the disease — one-third of patients with an exacerbation have reported recent NSAID use (Basson, 2019).

Pathophysiology

Ulcerative colitis usually begins in the rectum where it may remain localised or extend proximally, sometimes involving the entire colon (Walfish and Companioli, 2020b). Unlike Crohn's disease, ulcerative colitis does not affect other parts of the gastrointestinal tract (Bhat, 2021). Areas of the bowel affected are shown in *Table 5*. The inflammation caused by the disease affects the mucosa and submucosa and there is a sharp border between normal

and abnormal tissue (Walfish and Companioli, 2020b).

Signs and symptoms

Signs and symptoms differ in severity and vary from person to person (National Institute of Diabetes and Digestive and Kidney Disease [NIDDK], 2021). In milder cases, patients may have around four bowel movements each day with blood in the stool, while in more severe cases, patients may have six or more bowel movements per day with blood in the stool. Common symptoms include (NIDDK, 2021):

- ▶ Passing mucus with stools
- ▶ Diarrhoea
- ▶ Rectal bleeding
- ▶ Feeling the need to open the bowels even when the bowel is empty (tenesmus)
- ▶ Cramping stomach pains
- ▶ Those with more severe disease may have a fever, suffer with nausea or vomiting, weight loss and feel fatigued.

Diagnosis

After taking a thorough history and examination of the patient, NICE guidelines (2020b) advise initial investigations should include the following:

- ▶ Full blood count (FBC): may show anaemia caused by blood loss, malabsorption, or malnutrition. A raised platelet count may suggest active inflammation
- ▶ Urea and electrolytes (U&E): may show signs of dehydration (elevated serum urea)
- ▶ Liver function tests (LFTs): low albumin level reflects disease activity and severity as well as the patient's nutritional status
- ▶ Erythrocyte sedimentation rate (ESR) and C-reactive protein (CRP): raised levels may reflect infection or active inflammation
- ▶ Thyroid function tests (TFTs): to exclude any problems with thyroid function
- ▶ Serum ferritin, vitamin D levels, B12 and folate: may be reduced due to malabsorption
- ▶ Coeliac screen: to exclude coeliac disease
- ▶ Stool sample: tested for microscopy and culture, including *Clostridium difficile* (presence of a pathogen on testing does not

exclude a diagnosis of ulcerative colitis as a first episode may be triggered by enteric infection)

- ▶ Further investigations to confirm the diagnosis may include: X-ray or CT scan and, in addition, a sigmoidoscopy (to examine the rectum and sigmoid colon), and/or a colonoscopy to view the entire colon
- ▶ Faecal calprotectin: in adults, a raised result may indicate inflammation. Level is normal in irritable bowel syndrome (IBS).

Treatment and management

Treatment will aim to minimise symptoms and induce remission, and, wherever possible, keep symptoms at bay to maintain remission. Medication is initiated by secondary care as follows (NICE, 2020b):

- ▶ Amino salicylates: mesalazine and sulfasalazine may be given for mild-to-moderate first presentations, or can be used to maintain remission. They may be given in enema or suppository form initially, but switched to oral if remission is not achieved after four weeks of use. In extensive disease, both topical and high dose oral treatment may be offered first line
- ▶ Corticosteroids: may be given as monotherapy (topically, orally or intravenously) to induce remission if amino salicylates are unsuitable or not tolerated. They are unsuitable to maintain remission due to the risk of multiple adverse effects
- ▶ Calcineurin inhibitors: tacrolimus or ciclosporin may be added

Red Flags

- Most prevalent in younger adults aged 15 to 25 years
- Similar to Crohn's disease, in that it follows a relapsing, remitting course
- Affects only the bowel
- Best prognosis seen in those with disease localised only to the rectum
- Worst prognosis in those with diagnosis at a young age, severe symptoms at diagnosis, and extensive disease.

Table 5: Areas of the bowel affected by ulcerative colitis (Bhat, 2021)

Area affected	Additional information
Rectum	The condition always involves the rectum and extends proximally. When only the rectum is involved, this is referred to as proctitis
Rectum and sigmoid colon	This is referred to as proctosigmoiditis
Entire colon	When the whole of the colon is affected, this is pancolitis
Muscularis propria (muscular layer of the bowel)	Colonic dilation caused by severe disease with inflammation of the muscularis propria and neuromuscular dysfunction leads to toxic megacolon — a potentially fatal complication

to corticosteroids if response is inadequate after two to four weeks, and may be used in those with mild-to-moderate disease

- ▶ Immunosuppressive drugs: azathioprine, mercaptopurine (thiopurines) or methotrexate (second line) may be an option to maintain remission if this cannot be achieved with amino salicylates. They are also used to maintain remission when corticosteroids have been required for two or more inflammatory exacerbations in a 12-month period. Patients need to be advised of the increased risk of non-melanoma skin cancer. Regular monitoring and sun protection advice is needed
- ▶ Biologic therapy: intravenous infliximab and subcutaneous adalimumab and golimumab are used to induce remission in people with severe active disease if conventional treatments have been ineffective or are unsuitable. They can also be effective in maintaining remission
- ▶ Surgery: surgery may be needed for those who fail to respond to medications, or who are experiencing severe or frequent flare ups that are impacting on their quality of life. See *Table 6*.

Complications

Patients with extensive ulcerative colitis over a long period have a significantly increased risk of colorectal cancer and this risk is higher in those whose disease onset occurred before the age of 15, or who have pancolitis (Basson, 2019; *Table 5*). Toxic megacolon is the most common cause of death and occurs when inflammation of the colon causes the colon to be very dilated and may rupture (Basson, 2019).

Prognosis

Prognosis is dependent on several factors. The disease is usually a lifelong chronic condition with periods of remission and exacerbations. The best prognosis is seen in those with localised ulcerative proctitis (Walfish and Companioni, 2020b), while the worst is seen in those with severe symptoms at presentation, extensive disease, young age (particularly childhood onset), raised

inflammatory markers, and patients who are non-compliant with treatment (NICE, 2020b).

CONCLUSION

Gastrointestinal diseases are highly variable in their presentation, treatment, impact on patient health and wellbeing, and can affect any part of the gastrointestinal tract. This article has focused on only three of many diseases, but hopes to give community nurses and non-medical prescribers a brief insight into their recognition and management, with the aim of increasing confidence and knowledge of the diseases discussed.

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Table 6: Surgical options for ulcerative colitis (Crohn's and Colitis Foundation, 2021)

Surgical procedure	Additional information
Colectomy with ileostomy (subtotal)	This is the commonest type of surgery. The colon is removed, but the rectum remains. The end of the small intestine is brought to the surface of the abdomen, forming an ileostomy which may be temporary or become permanent
Restorative proctocolectomy with ileo-anal pouch	This procedure is commonly called pouch surgery, but may also be described as IPAA (ileo pouch-anal anastomosis) surgery. It generally requires two or three operations, but in rare circumstances may be done as a single stage. In the first operation, the surgeon removes the whole colon, but leaves the rectum and the anus. As with the subtotal colectomy described above, a temporary ileostomy is then formed to collect waste from digestion. At this stage, patients are generally able to stop taking medications for their ulcerative colitis. During the second operation, a pouch is made using the ileum which is joined to the anus. The pouch stores stool until it can be passed out of the body in a bowel movement. For patients having a two-stage procedure, the pouch is created in the first operation. A section of the small intestine is then brought out through an opening in the external wall of the abdomen to create a temporary ileostomy, giving the newly formed pouch a chance to heal, which generally takes about three months. The temporary ileostomy can then be closed in the second or third operations, so the pouch can be used. The main advantage of a pouch is that faeces can be passed through the anus in the normal manner, although more frequently than normal. Many people have about six bowel movements a day, plus one or two at night. Some people also experience incontinence after pouch surgery
Proctocolectomy with ileostomy	This involves the removal of the entire colon, together with the rectum and the anal canal. The end of the lower small intestine is brought out on to the wall of the abdomen to form an ileostomy. A bag is fitted onto the opening to collect the waste from the small intestine. This can be emptied or changed as necessary. This surgery is irreversible
Colectomy with ileo-rectal anastomosis	This operation is rarely performed, as it is only suitable for a few with this disease. The colon is removed and the end of the small intestine is removed and joined directly to the rectum. This avoids the need for an ileostomy, so it may be useful for people who could not cope with a stoma or who are unsuitable for pouch surgery. It is only recommended if there is little or no inflammation in the rectum and low long-term risk of developing rectal cancer

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KEY POINTS

- Gastrointestinal diseases are highly variable in their presentation, treatment, impact on patient health and wellbeing, and can affect any part of the gastrointestinal tract.
- Many can occur at any age, although as with other conditions, some are more prevalent in specific age groups.
- Diverticular disease occurs when there is the development of a sac-like protrusion in the muscular wall of the colon.
- Crohn's disease is a chronic relapsing and remitting, non-infectious disease of the gastrointestinal tract.
- Ulcerative colitis is a form of inflammatory bowel disease characterised by diffuse inflammation of the colonic mucosa, affecting the rectum and extending along a variable length of the colon.
- This article hopes to give community nurses and non-medical prescribers a brief insight into the recognition and management of these three diseases, with the aim of increasing confidence and knowledge.

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Revalidation Alert

Having read this article, reflect on:

- Your knowledge of gastrointestinal disorders
- How you would recognise the signs and symptoms of diverticular disease, Crohn's disease and ulcerative colitis
- Treatment options available for the three gastrointestinal disorders discussed here.

Then, upload the article to the free JCN revalidation e-portfolio as evidence of your continued learning: www.jcn.co.uk/revalidation

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Safeguarding: recognising, reporting and recording adult abuse

Darren Butler

Adult safeguarding is the process of protecting an adult's right to live in safety, free from abuse and neglect (NHS England, 2017). High profile abuses such as Winterbourne View and Mid Staffordshire, as well as other cases, have raised the awareness of adult safeguarding, which is everybody's responsibility. In the community setting, it is paramount that nurses from all specialisms know how to recognise, report and record abuse. The Care Act (2014) recognises ten types of adult abuse and within them there are many forms that these can take (Department of Health and Social Care, 2021). Community nurses should be able to recognise such abuse and its effect on the victim, and know how to record their concerns in a clear, robust manner, ensuring that information is shared between agencies, while also respecting confidentiality. This article provides a brief history of adult safeguarding, an overview of the types of abuse, as well as a definition of the vulnerable adult, how to recognise them, and the statutory bodies and legal frameworks to safeguard adults. Each of the four nations of the UK have their own legislation. This article is concerned with safeguarding in England and the Care Act (2014).

KEYWORDS:

■ Adult safeguarding ■ Recognising adult abuse ■ Reporting and recording adult abuse

In 1998, a White Paper by the Department of Health (DH), *Modernising Social Services*, signalled its intent to improve the protection of individuals needing care and support. The Department of Health and Social Care subsequently published *No Secrets: guidance on protecting vulnerable adults in care* (2000), which offered guidance for social care, health providers, the independent sector, and carers and service users. This was an attempt to highlight the need for transparency when exposing the abuse of vulnerable adults. It also aimed to

protect victims and witnesses when reporting abuse. Implementation of these guidelines was to be coordinated by local authority social service departments. *No Secrets* was in line with the government's aim to respect human rights and the Human Rights Act (1998), which was also due to be implemented at that time. Although each local authority would coordinate these guidelines, responsible agencies, such as the police and various NHS organisations (hospitals, community, ambulance service), were required to work together to provide a consistent and coherent safeguarding policy, as well as an effective response to safeguarding concerns.

Effective prevention was the primary strategy, and, if that failed, a robust plan was to be put in place to safeguard the individual. The

No Secrets document provided a definition of a vulnerable adult as an individual 18 years and over who was receiving or needed community care services due to mental/physical disability, or due to age or illness and were/potentially unable to care for themselves or protect themselves from significant harm or exploitation. The document also defined abuse as a 'violation of an individual's human and civil rights by any other person or persons' (DH, 2000: 9). It could be a single or repeated act, and lead to significant harm or exploitation.

Abuse could be as a result of deliberate action, negligence or ignorance. Some acts could meet a criminal threshold, such as theft, fraud, assault, rape and discrimination (for example, racial and gender). It stated that abuse could occur to one person at a time, or be done to multiple individuals. It acknowledged that if there was a suspected criminal act committed in relation to the abuse, police should be notified urgently, and the police investigation would take priority over other lines of enquiry. The document drew attention to who could be an abuser, citing relatives, professional staff, paid care workers, volunteers, other service users, strangers, and people who deliberately exploit vulnerable adults. It stated that the response in investigating the abuse may depend on the alleged abuser and the circumstances. For example, hospitals are subject to legislative regulatory controls, whereas personal family settings would have their own complexities requiring a different response.

No Secrets (DH, 2000) also provided guidance on what level of abuse justified intervention.

Darren Butler, named nurse adult safeguarding, RN, DN, Cambridgeshire and Peterborough NHS Foundation Trust

It advised objectivity and consideration of:

- ▶ The individual's vulnerability
- ▶ The nature and extent of the abuse
- ▶ The duration of the abuse
- ▶ The impact of the abuse on the vulnerable adult
- ▶ The risk of repetition.

DEFINITIONS

Every individual has the right to live a life free from neglect and abuse. They have the right to live in safety. This is firmly rooted in the Human Rights Act (1988). This protects everyone in the UK, whether or not they are a UK citizen, or an asylum seeker. The Act states that public authorities must respect and protect an individual's human rights. Examples of human rights include a person's right to non-discrimination (article 14), and prohibition of slavery and forced labour (article 4) (Citizen's Advice, 2021). Adult safeguarding means protecting those rights. Most adults are able to protect themselves from abuse and to live in safety. However, adults at risk of abuse/neglect are unable to do this and will need to be safeguarded. As stated, safeguarding is everybody's concern and health and social care professionals have a safeguarding responsibility. It is important to note that a variety of other groups are also responsible (including police, adult education, family, members of the public, and sometimes the individual themselves).

An adult at risk is a person aged 18 years and over who is at risk of abuse/neglect because of their care or support needs (NHS England, 2017). In the author's opinion, this could be, for example:

- ▶ An adult in a nursing or residential home
- ▶ An adult cared for by a friend/family member, or who has domiciliary care
- ▶ Someone who is at risk of self-neglect and is therefore in need of care
- ▶ A patient receiving care as an inpatient
- ▶ An adult who is receiving care from a mental health team in the



'... safeguarding is everybody's concern and health and social care professionals have a safeguarding responsibility.'

community or in a mental health setting.

THE CARE ACT (2014)

The Care Act (2014) sets out legal guidance as to how local authorities and other organisations should protect adults at risk of abuse and neglect. Local authorities must lead local adult safeguarding systems, which should prevent abuse and act rapidly when it occurs. When there is a concern that an adult is at risk of abuse, local authorities must make enquiries or request other organisations to do so (Care Act, Section 42). Each area should also establish safeguarding adult partnership boards (SAPB) (Care Act, Section 43).

When an adult suffers abuse/neglect or dies as a result of abuse/neglect, the SAPB needs to arrange an adult safeguarding review (SAR) to establish if the local authority and other agencies could have done more to protect them (Care Act, Section 44).

The Act also requires local authorities to arrange for an advocate for the adult if needed

at a safeguarding enquiry/review (Care Act, Section 68) (Social Care Institute for Excellence [SCIE], 2021).

WINTERBOURNE VIEW AND MID STAFFS SCANDALS

Widely publicised adult abuse cases, such as Winterbourne View and the Mid Staffordshire scandal, have led to a higher profile of adult abuse and shaped government health and social care policy. They have also guided safeguarding policies for organisations and professional bodies.

Winterbourne View

Following five weeks of covert filming by the BBC programme, 'Panorama' (broadcasted 31 May, 2011), which documented serious abuse at a residential hospital, four people were arrested by the police. The hospital provided care for clients with learning disabilities and autism. The hospital's owners, Castlebeck, suspended thirteen employees. The Care Quality Commission (CQC) were asked to conduct an urgent investigation. Examples of the abuse filmed included clients being pinned down, slapped, taunted and teased, as well as being dragged into showers while fully clothed.

The 'whistleblower' who brought his concerns to the BBC stated that the CQC and management at Winterbourne View had been informed in the past of concerns, but that his complaints had not been

acted on. This led to an internal review by the CQC and an apology for missed opportunities to act. It also led to South Gloucestershire Council informing the safeguarding adult board (SAB) and appropriate action being taken in line with procedures and protocols.

By 19 January 2012, 11 people had been charged with allegations of abuse at the home. By 18 April 2012, nine of those individuals admitted to charges. It also led to two council managers responsible for adult safeguarding being sacked (www.bbc.co.uk/news/uk-england-bristol-20078999).

Winterbourne View is an example of a failure to act when concerns are raised. The independent serious case review found that from the year the home was opened to when it closed (2006 to 2011), there were 38 safeguarding alerts concerning 20 patients, and only one in five of those was reported to the NHS. The report's author, Margaret Flynn, concluded that there was an attitude of 'out of sight, out of mind' when addressing the allegations by the primary care trusts when placing the adults in Winterbourne View. She stated that Castlebeck appeared to put decisions about profitability over effective and humane care. The report stated that staff were 'chronically bored' and 'poorly managed'. Avon and Somerset police were also criticised, as they failed to recognise a pattern of 29 calls and nine incidents reporting abuse and concerns over three years. Furthermore, the CQC were criticised and accepted the recommendations made by the report.

Dr Gabriel Scully (NHS Review Chair) highlighted that there was

Practice point

The Winterbourne View and Mid Staffs scandals are high profile cases of organisational abuse. They include examples of neglect and acts of omission, psychological and physical abuse.

no organisation/individual who was able to piece together the concerns from different organisations (www.bbc.co.uk/news/uk-england-bristol-20078999).

In October 2012, six individuals were jailed and five were given suspended sentences for 'cruel, callous and degrading' abuse of the adults at Winterbourne View. In total, there were 38 charges of neglect and ill treatment of five people with learning difficulties (Hill, 2012).

Mid Staffs scandal

Between January 2005 and March 2009, it is estimated that between 400 and 1,200 patients died as a result of poor care at Stafford hospital run by Mid Staffs NHS Trust (Campbell, 2013).

- Examples of abuse included:
- ▶ Patients being left in their own faeces and urine in soiled clothes and sheets for long periods of time
 - ▶ Staff not assisting patients who could not eat and drink independently
 - ▶ Water being left out of reach
 - ▶ Patients not being assisted to go to the toilet despite repeated requests for help
 - ▶ Ward and toilet facilities being left in extremely unsanitary conditions
 - ▶ Patients being denied dignity, even when they were end of life
 - ▶ Untrained staff triaging patients in the accident and emergency department
 - ▶ Staff appearing to treat patients and those close to them in an indifferent and callous manner.

The Francis Report (Stationery Office, 2013) concluded that there was:

- ▶ A lack of basic care across the ward/departments across the trust
- ▶ The trust culture was not conducive to supporting staff and providing care to patients. There was an atmosphere of fear of adverse repercussions if concerns were raised. Instead, there was a focus on achieving targets, a lack of openness and consultants. As

- a result, there was low morale
- ▶ Trust management was more focused on financial targets and achieving foundation trust status. This was to the detriment of patient care
 - ▶ Longstanding deficiencies in staff and governance were not addressed by trust management through the governance process
 - ▶ There was a lack of urgency and transparency (both internal and external) to address these issues
 - ▶ There was a focus on statistics and data rather than asking patients to feed back their experiences.

RECOGNISING ADULT ABUSE

It is important to note that an adult can be a victim of more than one type of abuse and the duration can be very short or last a number of years. It can lead to distress, injury or death. Therefore, recognising the types of abuse, when to act, and how to act is extremely important.

The Care Act (2014) identifies ten categories of abuse, as follows.

Physical abuse

This can include punching, hitting, slapping, restraint, unsafe moving and handling techniques, as well as the inappropriate use of medication, for example, covertly administering a sedative so a patient will not disturb staff.

Sexual abuse

This can include sexual assault, rape, inappropriate touching, subjecting someone to watch pornography against their wishes.

Psychological abuse

This can include humiliation, verbal abuse, bullying, and coercion (coercion is a criminal offence; Serious Crime Act, 2015).

Modern slavery

Examples include forcing an individual into servitude, or forced labour. This can be domestic work, nail bars, hand car washes, illegal activity, e.g. prostitution and cannabis farms. It can involve human trafficking (Modern Slavery Act, 2015).

Financial or material abuse

This includes theft, fraud, scamming, and rogue traders. Perpetrators can be health and social care workers, members of the public and family/friends. If this type of abuse is carried out by an employed member of an organisation, a safeguarding referral can be made in the public interest. An example would be if a service user discloses to a district nurse (DN) that their carer has stolen money from them on a home visit. In this instance, a safeguarding referral should be made as other service users could be at risk from this carer.

If a service user (with mental capacity regarding a safeguarding referral) discloses to a DN that their adult relative is stealing money from them, verbal consent should be sought for a safeguarding referral. This is because the abuse is by a family member not involved in the care of other individuals. The service user has the right to decline a referral. However, it is advised that advice from a safeguarding lead is sought and that consent is offered as long as the concern exists. In the author's clinical opinion, if they lack capacity regarding accepting/declining a referral, a referral can be made in their Best Interests.

Neglect and acts of omission

This involves failure to provide access to appropriate health, care or educational services. It also includes the withholding of necessities of life (food, fluids, medication, heating). Neglect can be unintentional or deliberate. In the context of nursing, pressure ulcers can be as a result of neglect. If an individual acquires a pressure ulcer because staff failed to refer to a DN or tissue viability nurse (TVN) in a timely manner, or failed to reposition and monitor the patient's skin, in the author's clinical opinion, this could be classed as neglect.

Self-neglect

This refers to an inability to engage with clinical treatment or social care, i.e. non-engagement with services. Examples would include a service user who is declining

personal care and therefore not having their hygiene needs met. It could also be an individual who is living in squalor and cluttered conditions. Self-neglect can be at various levels. The risk can be very low, i.e. a service user with minimal self-neglect would be someone living in a low level of clutter and squalor. They would have poor hygiene but would concord overall with services. This individual would require case management to help

'It is always preferable to manage self-neglect in partnership with the patient. If the service user has the decision-making capacity to consent, this should be sought to make a referral to the multi-agency safeguarding hub.'

them manage their health. A high-risk self-neglect patient would be someone living in extreme squalor and a very cluttered environment. Their property could have vermin infestation, unhygienic conditions (animal/human faeces). The gas/electricity/water could be switched off. The property could have unstable masonry (all examples given anecdotally to the author by colleagues). The self-neglect would be highly detrimental to physical and mental health and there would be a risk of hospital admission.

When managing self-neglect, healthcare professionals should consider how high the risk to well being is and also to other people. They need to take into account the individual's mental capacity and undertake a mental capacity assessment (MCA) if required. Healthcare professionals should always remember that MCAs are decision- and time-specific.

It is always preferable to manage self-neglect in partnership with the patient. If the service user has the decision-making capacity to consent, this should be sought to make a referral to the multi-agency

safeguarding hub (MASH; see below) or other support services. If the risk is so high that there is a risk to life and limb (sepsis, infection, etc) or in the public interest, or if an MCA is done and the individual is considered not to have capacity (regarding the decision to accept/decline a referral to the MASH), a referral can be made in their Best Interests.

Although a DN can raise a self-neglect concern within their trust without consent, as this concern has not gone outside the organisation, if they refer to the MASH without consent for self-neglect, this will be rejected, as confidentiality has been breached.

In the author's clinical experience, self-neglect is a category of abuse that can be challenging for nurses to recognise and manage.

Domestic abuse

This is a category of abuse that can include sexual, physical, psychological and financial abuse. It is abuse that occurs between two people who were or are in a relationship (16 years and over). Generally, for a safeguarding referral to be made, verbal consent must be sought and the individual should have care and support needs. If this is done without the client's consent, it will result in a breach of confidentiality. If an individual does not have care and support needs, with consent, referrals can be made to other domestic abuse support organisations, such as the National Domestic Abuse Helpline. An example of an individual without care and support needs could be an individual who visits the general practice nurse (GPN) for a vaccination and discloses that they are a victim of domestic abuse.

In the author's clinical experience, exceptions where consent might not be sought are if the domestic abuse is witnessed by the healthcare professional, or there is a risk to life and limb, or children are involved. In these instances, advice from a safeguarding lead and

senior management should be sought.

Discriminatory abuse

This is abuse of an individual due to their gender, race, ethnicity, religion, sexual orientation, religion or beliefs.

Organisational abuse

This is neglect of individual(s) by an organisation. This can be as a result of poor management structures, lack of training and staff support. It can be over a long period of time or recent.

MAKING SAFEGUARDING PERSONAL (MSP)

MSP is an underpinning principle of adult safeguarding and was first introduced by the DH in 2011 and then embedded into The Care Act (2014). The Act made it clear that adult safeguarding should be person-centred and, where possible, safeguarding referrals and actions should be consent led. The statutory guidance set out six principles to guide professionals (SCIE, 2020), namely:

- ▶ Empowerment: supporting and encouraging individuals to make their own decisions
- ▶ Prevention: to be proactive before abuse occurs
- ▶ Proportionality: the least intrusive response which is appropriate to the risk
- ▶ Protection: support those in greatest need
- ▶ Partnership: local solutions through services and communities working together. Importance of communities' responsibility in recognising and reporting abuse
- ▶ Accountability: transparency when safeguarding adults.

REPORTING ADULT ABUSE

Most local authorities have a multi-agency safeguarding hub (MASH) for safeguarding referrals to be made into. Each local authority will have different methods of referring (online/phone). A list of contact details for the MASHs in England can be found on the NHS safeguarding app from the Apple

and Play stores. When referring to the MASH, it is best practice to clearly document if consent has been sought and, if not, why, and what outcomes the person wants the process to reach (Cambridgeshire and Peterborough Safeguarding Partnership Board, 2021a). Mental capacity should also be considered if appropriate. A clear description of the abuse should be documented and what the service user's wishes are regarding the management of the abuse (MSP).

'Whether or not a safeguarding referral is made, abuse should be documented and the line manager/senior management or the organisation's safeguarding team made aware. An incident form is an effective way of doing this.'

The MASH will decide if the referral meets the safeguarding threshold. Actions can include instigating a Section 42 enquiry (a formal safeguarding investigation). The local authority will lead on this and a social worker will start the investigation and chair any meetings. All meetings should have minutes taken. Invitations will be sent to the professionals who are working with the service user and the service user and/or an advocate will be invited unless inappropriate. If the allegation is against an agency, they may also be invited. There will be as many meetings as required to establish if the abuse is taking place and an action plan should be produced to safeguard the person. There should also be an opportunity to highlight good practice and areas of improvement (Cambridgeshire and Peterborough Safeguarding Partnership Board, 2021b).

Some referrals will be forwarded to a social team for case management instead of an investigation. This is a means to support the individual who is still currently at risk where a Section 42 enquiry is not needed. Some

referrals may be noted as a concern (particularly from a care agency or care home) if the risk is low, but the standard of care needs improvement.

Another means of safeguarding an individual is to hold a multi-agency risk management meeting (MARM). This is a way of supporting a person who is self-neglecting, has capacity regarding their behaviour, is declining services and undertaking very risky behaviour (for example, recreational drug use). Again, the individual will be invited, or an advocate can attend. This will be chaired by a senior social worker and all the professionals involved in the care of the individual will be invited, such as the GP, police, housing association, health and social care, among others. This is not statutory and may vary across England.

In some cases, the safeguarding referral may be deemed not to meet the threshold and no further action will be taken.

Finally, consideration needs to be given to where the abuse occurs geographically. If an abuse is disclosed to a DN in, for example, Cambridgeshire, the referral will be made to the Cambridgeshire MASH. However, if the service user discloses to the DN about an abuse that happened in a hospital or another setting that is in a different local authority area, the DN will refer to that authority's MASH. This can occur regularly as healthcare professionals in the community will cross county borders to visit patients.

RECORDING ADULT ABUSE

Whether or not a safeguarding referral is made, abuse should be documented and the line manager/senior management or the organisation's safeguarding team made aware. An incident form is an effective way of doing this. In the author's clinical experience, supervision with the safeguarding lead/named nurse or team members is also an effective way to seek support and advice regarding a

safeguarding concern. It is important to note that the incident form and team meetings/supervision are within the organisation and to maintain appropriate confidentiality.

It is advisable that minutes of meetings and a record of emails/conversations are kept in case the concern escalates. Documentation should be clear, accurate and recorded in a timely manner. To respect patient confidentiality, information should only be shared with other organisations if relevant to the abuse, and if consent has been obtained or a Best Interest decision has been made where a person lacks relevant capacity. It can also be shared if in the public interest.

CONCLUSION

Safeguarding is everybody's concern. Community nurses need to ensure that they can recognise adult abuse and are aware of the different categories. They need to be able to record their findings clearly and accurately and know how and when to refer to the MASH, taking into account confidentiality, consent, and when and how to make an MCA Best Interest decision. **JCN**

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KEY POINTS

- Adult safeguarding is the process of protecting an adult's right to live in safety, free from abuse and neglect.
- In the community setting, it is paramount that nurses from all specialisms know how to recognise, report and record abuse.
- The Care Act (2014) sets out legal guidance as to how local authorities and other organisations should protect adults at risk of abuse and neglect.
- Widely publicised adult abuse cases, such as Winterbourne View and the Mid Staffordshire scandal, have led to a higher profile of adult abuse and shaped government health and social care policy.
- It is important to note that an adult can be a victim of more than one type of abuse and the duration can be very short or last a number of years.
- Adult safeguarding should be person-centred and, where possible, safeguarding referrals and actions should be consent led.
- Most local authorities have a multi-agency safeguarding hub (MASH) for safeguarding referrals to be made into.
- It is vital to know how and when to refer to the MASH, taking into account confidentiality, consent, and when and how to make an MCA Best Interest decision.

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My community



Jane Hampton, consultant nurse in wound management, Aarhus Municipality, Denmark

WHAT IS YOUR BACKGROUND IN COMMUNITY NURSING?

I qualified as a nurse in New Zealand, and first worked in the community as an agency nurse in Southwest London in 1992 while doing my OE (overseas experience), and I have been in the primary care sector ever since. I started as a community nurse before becoming a district nurse team leader and then in 1998 a tissue viability nurse (TVN). I've continued to work as a wound specialist nurse and am still 'overseas', but now in Aarhus, Denmark, where I've been the last 15 years. Today, I work in a team of four wound specialist nurses tasked with improving wound management for patients in a variety of community settings.

WHAT DOES YOUR TYPICAL DAY LOOK LIKE?

No one day is the same, which is also why the job is so interesting. The largest part of our time is used advising nurses on evidence-based wound care. This can involve visiting a patient at home, in a health clinic or nursing home, always with the contact-nurse so that bedside learning can occur. We receive referrals throughout the day and advice is frequently given electronically, via the electronic patient journal or electronic wound journal.

Every week we also find time for other activities, such as developing care pathways, providing teaching both online and in person, communicating with the hospital TVNs on shared patients, coordinating small research projects evaluating a new product or initiating new ways of working.

DO YOU HAVE ONE EXPERIENCE THAT HAS TAUGHT YOU SOMETHING VALUABLE?

Community nursing services are not particularly visible, as

nurses are usually alone with the patient behind closed doors. It has been important for us to collect data to demonstrate the effect of our activities on both service quality and the organisation's finances. For example, our organisation treats 30% more patients with wounds today than four years ago, but the annual number of patient contacts for dressing changes has remained the same, while healing rates have improved. This is only possible through improving nurses' knowledge of wound treatment. Being able to present such data has led to our specialist team becoming permanently employed rather than a temporary project.

HOW DOES WORKING IN A NORDIC COUNTRY COMPARE TO OR DIFFER FROM THE UK?

Access to health care is free to Danish citizens and publicly funded via taxes as in the UK. Community nurses, healthcare assistants and homehelps are all employed by the municipality and often employed in the same teams. Community nursing is available 24/7, and the services provided are largely the same as in the UK.

A difference is perhaps the widespread use of digital communication. All patient documentation in Denmark is digital, although different systems are used throughout the country:

- ▶ Community nurses have a personal tablet containing the community patient journal. GPs and community nurses can communicate electronically via the patient journal, although we do not have access to each other's records. This has considerably reduced telephone use
- ▶ An electronic Shared Medicine Card means all healthcare professionals can see the patient's current up-to-date prescribed medicines
- ▶ A national telemedicine wound journal allows hospital wound clinics and community nurses to see each other's photographs and documentation for shared patients. This has immensely improved continuity of treatment and patient outcomes.

Denmark does not have nurse prescribing or national quality targets in primary care, and it is only this year that the first advanced nurse practitioners (ANPs) have graduated into the workforce.

WHAT ONE THING WOULD MAKE THE MOST DIFFERENCE TO YOUR PRACTICE?

Health laws in Denmark do not allow nurses to start a clinical intervention, such as compression bandaging for oedema or venous leg ulceration, without a doctor's permission. The nurse who has assessed the patient has to write to the GP for confirmation that the observations fit the use of compression. This often delays the start of optimal treatment, especially if the GP decides to see the patient first. A change in law in Denmark allowing nurses to make independent decisions within their competency levels would make my practice more effective for patients. **JCN**

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Patient Height	Patient Weight	Model	PIP Code
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	10 - 16 Stone (64 - 102kg)	MP80 Average Build	320-0045
	16 - 22 Stone (102 - 140kg)	MP180 Large Leg	320-0060
Under 5'5" (165cm)	Up to 10 Stone (64kg)	MP76S Slim Leg Short	333-7599
	10 - 16 Stone (64 - 102kg)	MP80S Short Leg	320-0052
	16 - 22 Stone (102 - 140kg)	MP180S Large Leg Short	320-0078



Limbo Model	Upper Arm Circumference	PIP Code
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