END OF LIFE CARE

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Delivering better end of life care

Macmillan Policy Manager, George Holley-Moore, on Macmillan’s new programme to help improve end of life care across the UK.

Macmillan has a long and rich history in end of life care. As people approach the end of their life, they often have many physical, emotional and practical needs. High quality end of life care is at the heart of our strategy. We actively campaign for improvements to benefit everyone at the end of life, not only people with cancer.

By 2040, annual deaths in England and Wales are calculated to rise by 25%1. Due to an ageing population, people are increasingly dying with two or more long-term conditions.

It is vital that our healthcare system is equipped for the growing number and complexity of deaths in future years. Macmillan has launched an End of Life Care Programme to help achieve this. We have also published a report urging the government to deliver on their promise to improve end of life care.

Macmillan’s End of Life Care Programme

From April 2019 to December 2022, we will develop end of life care ‘collaborative sites’. The term ‘collaborative’ reflects a co-working ethos between different parts of the local health and social care system, through development towards an exemplary service. These sites will help us fully understand what makes good end of life health and social care in the community and how we can practically implement this.

We hope to spread best practice, leading to the creation of further collaborative sites. Our ambition is that 30% of people with cancer at the end of life will eventually benefit.

The programme also seeks to identify the learning and development needs of the end of life care workforce. We are currently reviewing our learning and development offers and planning a palliative care conference.

New policy report

NHS England’s Long Term Plan pledges to redesign patient care over the next decade and recognises that end of life is a priority area for improvement.

Earlier this year, we published our report, At the crossroads: How can the NHS Long Term Plan improve end of life care in England?, based on the views of healthcare professionals. It recommends what must happen to translate the Long Term Plan into real change at a local level. Our influencing work takes place in all four nations, but this report focuses on England, in response to the Long Term Plan.

Following in-depth interviews and focus groups across various health settings, we drew up a list of seven main policy recommendations in our report:

- The need to prioritise end of life care: NHS England should provide clear guidance on what local health systems are expected to deliver and prioritise in relation to end of life care. When they prepare their five-year delivery plan, every local health system should state how they intend to fulfil the end of life commitments in the Long Term Plan.
• **Personalising care at the end of life:** NHS England should ensure that local health systems offer an advance care planning conversation to everyone who may be in their last 12 months of life. This is key to personalising end of life care and involving a person’s carers and loved ones in decision-making.

• **Sharing patient records:** There should be suitable technology in place to give multiple professionals quick access to patients’ end of life records. However, the roll-out of Electronic Palliative Care Coordination Systems (EPaCCS) varies across the country. The main challenges reported were ‘clinical buy-in, functionality and data sharing’, and these issues need to be resolved.

• **Integrating care in the community:** NHS England should give guidance to ensure that rapid and urgent response teams have the right skills, competencies and experience to support people at the end of life.

• **Training professionals:** All relevant health and care professionals should be able to access funded training for improving their confidence to support people at the end of life.

• **A whole system approach to enabling personalised care:** The upcoming Spending Review should provide urgently-needed funding for social care. There should be a sustainable funding settlement in the long term.

• **Quality improvement in primary care:** NHS England should report on progress made against the Quality Improvement module for end of life care, set for 2019/20.

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**At a crossroads**

Our report concludes that we are at a crossroads for end of life care in England. NHS England’s Long Term Plan creates welcome opportunities to improve future care. Yet, as a healthcare professional told us, ‘Of course the national ambitions are good sense, and no one can disagree with them, but they just seem to be there and have no drive behind them.’

National and local systems must now work together to seize the opportunities in the Long Term Plan and deliver tangible results. We urge policy makers to follow the practical recommendations in our report and, over the next 10 years of the NHS, make England a better place to die.

To read our full policy report, visit macmillan.org.uk/crossroads

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**Further information**

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As Macmillan Specialist Adviser for End of Life Care, I provide leadership and expertise to the organisation. This involves advising on strategy, spend, policy, media and learning and development. I also provide external advice and expertise to other organisations, partnerships and groups. I work alongside Lucie Rudd, End of Life Care Adviser (currently on maternity leave).

My role involves working closely with Macmillan colleagues and professionals across the UK. Although Macmillan is a cancer charity, our work in end of life care aims to support all those with a life-limiting illness.

My passion for improving palliative and end of life care came about through personal and professional experience. I spent a large part of my early career as a district nursing sister and practice educator. I then moved on to more strategic roles focusing on end of life care in a variety of settings, including a primary care trust, cancer networks and strategic health authorities. I was also a trustee at my local hospice for several years.

I have worked at Macmillan for nine years and am delighted that end of life care remains a high priority for the organisation. Over the past few years, we have been supporting the development of Macmillan’s strategy for end of life care (see page ii for more details). And over the next few years, we will be working in partnership with existing end of life services across the UK, to embed this approach further.

Another key part of my role at Macmillan is to support media activity. This year, Lucie and I have used media opportunities to raise awareness of death and dying, and try to reduce the associated taboos within our society. We have participated in TV and radio interviews, as well as the You, Me and the Big C podcast and the Standard Issue podcast, as part of our #Letstalkaboutdeath campaign.

Outside of Macmillan, I am co-chair of the Ambitions Partnership for Palliative and End of Life Care for England. This is a broad partnership of national organisations who have come together to improve the quality and accessibility of palliative and end of life care (endoflifecareambitions.org.uk). I also represent the Ambitions Partnership on the National End of Life Care Programme Board for England.

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Read Adrienne’s article about her personal experiences with death and dying, published in iNews, at bit.ly/2nvr8g1 You can listen to the You Me and the Big C podcast at www.bbc.co.uk/programmes/p070s3z1 and the Standard Issue podcast at bit.ly/2o5Gs3l

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Butterfly Cornwall is a scheme to improve the way people with cancer and their loved ones spend their last days together at the Royal Cornwall Hospitals Trust (RCHT). Sadly, many people will be in hospital at the end of their life, and our scheme aims to enhance the quality of that time.

Staff can give extra support such as offering refreshments, providing comfort bags (which include essentials for relatives such as shower gel and toothpaste), and keeping noise and unnecessary interruptions to a minimum.

RCHT has adopted a yellow butterfly emblem to identify patients receiving end of life care. This can be seen across our hospitals on items such as discreet stickers or magnets by someone’s bed space, dignity curtain clips and on the patient flow system.

The scheme starts with initial training for patient-facing staff in each area, and happens on the ward to minimise disruptions and ensure the team is present in case of an incident or emergency. The training covers the principles of the Butterfly Cornwall scheme, communication, completing the priorities for care documentation, symptom management and anticipatory prescribing.

All staff on the ward are trained, including ward hosts, domestic staff and porters, ward clerks, healthcare assistants, therapists, doctors and nurses. The training can be delivered to staff across different roles within one area at the same time, as it is structured in three phases:

- all staff learn about the principles of the scheme and communication
- staff giving direct care then have documentation and symptom management training
- nurses and doctors are given further symptom management and medication management guidance.

This allows the flexibility to deliver training without disrupting the management of the ward. Staff can return to work once they have completed the sections relevant to their role.

To launch the scheme in an area, 50% of ward staff across the multidisciplinary team must have received training, and made a plan for how the scheme will embed within the team. We train senior nurses in each area to provide cascade training, and every member of staff who completes training receives a butterfly pin badge to wear on their uniform and a certificate for their Continuing Professional Development.

The scheme also includes:

- butterfly emblems, magnets and dignity clips (to be used with the patient’s or relative’s consent)
- open visiting and carer passports
- snack boxes from the helpdesk and hot and cold drinks from the ward
- comfort bags for relatives
- pet visits

Butterfly emblem helps to improve care

Steph Brelsford, Butterfly Scheme Project Lead, on a simple but effective way to improve care for patients at the end of life care.
• butterfly belongings bags for a person’s possessions after death

• wedding boxes for people at the end of life who wish to get married (including a guest book, confetti, a picture frame and a disposable camera, among other things).

• rainbow days – adding colour to someone’s last days by meeting a person’s wishes, such as a special meal, a haircut, a manicure or a massage.

A pre-training survey is completed initially, and a post-implementation audit has been conducted across all areas where the scheme is live. To date, 178 teaching sessions have been delivered with 691 people receiving ward-based training. The scheme has been positively received, with 88% of respondents stating that it has improved end of life care on their ward and 79% saying that it has influenced their practice. Butterfly Cornwall was recently shortlisted as a finalist at the National Patient Experience Awards 2019 in the category ‘support to caregivers, friends and family’.

We aim to improve and enhance end of life care through simple actions, which have a big impact for our patients and their families. We want to support them to spend quality time together when time is short. As a Macmillan Palliative Care Nurse, I have the opportunity to support teams across the hospital to meet the special needs of our patients. This is achieved through short training sessions, holistic support and facilitating experiences to bring joy and create memories to cherish.

Butterfly Cornwall’s ambition is that people at the end of life feel well cared for, that their loved ones feel well supported and that variations in care are reduced. This can have a huge impact on our staff. When we provide high-quality care, especially at end of life, the positives are wide-ranging and ripple throughout our teams and wards.

Butterfly magnets and clips.
Integrated learning in palliative care

Michelle Buono, Macmillan End of Life Education Nurse, on a new model of integrated learning to support end of life care in acute and hospice settings.

Between January and June 2018, we undertook an action research study to explore how best to obtain cohesive, collaborative working and meaningful learning between two services. Our aims were to support staff learning and improve palliative and end of life care for patients and families.

Both services – the Macmillan Unit at West Suffolk Foundation Trust (WSFT) and the Sylvan ward at St Nicholas Hospice Care (SNHC) – deal with complex symptom issues, and end of life care is part of the daily routine for nurses.

The study involved one-week shadowing placements for registered nurses, swapping between the WSFT Macmillan Unit and the SNHC Sylvan ward. They both occupy the same site in Bury St Edmunds.

The medical model of patient care adopted by many clinicians does not always allow for a more holistic approach. This is particularly so for patients requiring palliative and end of life care, especially when acute wards are busy, short staffed or manned by inexperienced and newly-qualified teams.

It is recognised that there is learning to be gained by shadowing in hospices, as these are environments where nurses gain an abundance of experience, knowledge and skills in caring for people near the end of their lives.

Gathering data

Volunteers were recruited at team meetings, and 12 nurses were selected on a first-come, first-served basis. Timings and shift patterns were negotiable when working ‘shadow’ shifts, depending on ward rotas and staff availability.

The study was run as an ‘action research’ project, which Waterman et al. define as ‘a period of inquiry that describes, interprets and explains social situations while executing a change intervention aimed at improvement and involvement.’

The nurses were asked to complete reflective diaries and feedback evaluation forms to illustrate the benefits and difficulties that they experienced during each shadow placement.

Before taking part in the study, the nurses had already identified two key potential learning areas – management of oncological emergencies in hospital and increased knowledge of medications used to manage:

- pain
- breathlessness
- nausea and vomiting
- agitation and restlessness
- secretions.

End of life care

Integrated learning in palliative care

Michelle Buono, Macmillan End of Life Education Nurse, on a new model of integrated learning to support end of life care in acute and hospice settings.
Findings
Four nurses returned reflective diaries, 11 returned evaluation forms and five returned reflective accounts by email. Triangulation of data identified strengths and areas for change.

Hospice nurses reported:
• acute skills refreshed
• IV competencies completed
• blood transfusion updates.

Hospital nurses reported:
• greater knowledge of holistic assessments
• confidence gained in end of life care giving
• enhanced understanding of emotional or family support.

Both groups reported:
• improved knowledge of using medications for end of life symptom management.

Impact
The integrated learning model has been developed as part of new training and educational initiatives offered by the WSFT palliative care team. This offers a two-day learning placement between services, accessible for all disciplines, to enhance palliative and end of life care skills. The two-year Macmillan Educator post has been extended for a further two years.

I am working with matrons and ward managers to cascade training to nurses from every area within WSFT, combined with regular placements from SNHC.

WSFT promotes learning to ensure that nurses working with adult patients, in any clinical setting, provide best-practice, holistic palliative and end of life care for patients and their families. This integrated model of learning enables flexibility to meet individual learning gives and can be offered to all disciplines at WSFT, including end of life ward champions, newly qualified staff and staff new to the trust. It provides ward managers with a model for upskilling nurses and learning opportunities for nurses to increase confidence and competencies, within acute or hospice settings.
The Preparation Star

Sara Burns, Director of Triangle Consulting Social Enterprise, introduces the Preparation Star tool to support people to talk about the end of life.

The Preparation Star is a new tool to help people talk about what matters to them when facing the end of life. This is often a difficult conversation, yet such an important one. It is a new version of the Outcomes Star, an evidence-based tool for supporting and measuring change (find out more at outcomesstar.org.uk).

The Preparation Star is a visual tool, centred around a star image with nine points – each representing an aspect of life which may be important to someone in their last months or years. This includes putting your affairs in order, family relationships, managing pain and doing what matters to you.

There is a scale for each area, underpinned by a five-stage ‘Journey of Change’ – where each outcome area is broken down into smaller steps, providing a way of consistently and objectively measuring progress.

When completed more than once, the Preparation Star can help professionals and others supporting people at the end of life to measure how things are improving. They can also recognise when things are as good as they can be, even if someone is very frail or unwell.

Developing the tool
The Preparation Star was developed by Triangle Consulting Social Enterprise through a collaborative process involving staff, patients and family members at North London Hospice, Jewish Care, the London ADASS End of Life Network and St. Joseph’s Hospice. Funded by a Macmillan grant, the process took more than two years. The pilot version was tested for a year before being finalised in early 2019 and published in October. This process and the pilot findings are outlined in a development report, available from Triangle.

Completing the Preparation Star is best done through a conversation between someone who knows they are dying due to a terminal diagnosis, or someone elderly or unwell, and a professional who is supporting them. It is available for any organisation or service supporting people at end of life, with a licence from Triangle. This includes training for workers, and potentially volunteers, to use the Preparation Star. There are additional resources for those wanting to complete it alone or in conversation with family, but currently they must receive a copy of our resources through an organisation or service.

Evidence from the pilot suggests that the Preparation Star is best used when someone is likely to have at least six months to live. In the last few weeks the focus is likely to narrow and there may not be the time or interest to look more broadly. So far it has worked best in a hospice outpatient wellbeing service, where there is a more holistic approach and it is relevant for professionals or volunteers to ask about the areas covered by the Preparation Star. However, we are keen to hear from people trying this in different contexts.

Feedback
I have led the development of more than 30 versions of the Outcomes Star for many different uses over 15 years, but I have felt most passionately about this one and was delighted to have the opportunity to work on it with others. So many people do not receive the support they need for their last months to be as good as possible. A large and increasingly recognised part of that is because so many of us are not comfortable
talking about death or simply don't know what questions to ask. Yet having that conversation can make all the difference.

The following are quotes from people using hospice well-being service:

- ‘The Preparation Star helped me to categorise the difficulties I am presently encountering, thus prioritising what is affecting me the most.’

- ‘It is a great tool. It helped me talk about important and very difficult things.’

- ‘It assisted my thinking in what I need to do next and to seek help in doing so. I can't do it alone.’

One professional also said, ‘The Preparation Star can assist the family in understanding where their family member is at in terms of their illness and emotional wellbeing, and in discussing things that they haven't been able to talk about yet.’

People have different needs and approaches and the Preparation Star won't be right for everybody. But if it can help even a few people to clarify and communicate what is important for them and live well right to the end, then that is a meaningful contribution.

For details of how to access the Preparation Star, call Triangle on 020 7272 8765 or visit www.outcomesstar.org.uk
The ReSPECT process: a new approach to emergency care planning in Scotland

Consultant Geriatrician and Macmillan Hospital Palliative Lead, Dr Lynsey Fielden, on person-centred emergency care planning.

Do not attempt cardiopulmonary resuscitation (DNACPR) decisions are commonly made in healthcare, but have been associated with negative perceptions, poorer outcomes and complaints. Evidence suggests that anticipatory/emergency care planning has over-focused on decision-making around CPR attempts, when such discussions should be considered as part of an overall treatment plan. This also provides an opportunity to consider realistic treatment goals with a shared decision-making approach.

The ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) process was created following a systematic review of DNACPR decisions and documents in 2015. It has been developed with wide stakeholder engagement and promoted by the Resuscitation Council (UK).

The process prompts individualised anticipatory care planning. This results in a summary document with personalised and realistic recommendations for a person’s care when they cannot make or express choices, and includes decisions about CPR. The process should respect both patient choice and clinical judgement. The form may support decisions around person-centred care planning, including a desire to remain at home for emergency care.

The ReSPECT form does not replace a conversation, when this can take place. However, in an emergency setting, the document could become an essential tool to guide individuals and teams to deliver the right treatment, at the right time in the right place, particularly for those approaching the end of life.

Demonstrating the need
In 2017, we analysed DNACPR documentation across NHS Forth Valley acute and community hospital wards, reviewing over 900 case notes. Over a third of patients had an NHS Scotland DNACPR (2016) form, which went up to 90-100% of patients in some community wards. A smaller study showed that only one in 10 patients had an emergency/anticipatory care plan, and there was no standardised framework for demonstrating a person-centred and shared-decision-making approach.

A hospital resuscitation service audit in 2017 identified that 32% of cardiac arrests resulted in CPR, which was potentially avoidable. The study showed that 6% of patients had an unrecognised pre-existing DNACPR decision and 8% had no clear escalation plan in place. The rate of survival to discharge after a cardiac arrest was 22% for all patients.

GPs in Scotland use the Key Information Summary (KIS) to record anticipatory/emergency care planning, which provides no standardised framework for documenting someone’s care preferences for an emergency situation. A significant proportion of health and social care professionals cannot access this information.

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Pilot stage
A pilot of the ReSPECT process was conducted from September 2017 to May 2018, in an older adult acute medical ward, an older adult acute mental health ward, Strathcarron day hospice and primary care (two GPs in different practices). A scanned copy of the ReSPECT form was available on the patient’s electronic health record, increasing visibility to care teams. We also adapted a trigger tool to prioritise care planning in a hospital setting.

We evaluated the ReSPECT process by reviewing:

- the ReSPECT process and quality of associated documentation
- patient outcomes, including preferred place of care
- Key Information Summary
- qualitative feedback from patients, carers and staff.

Key findings and next steps
Over 200 people experienced the ReSPECT process. At the time of writing, more than 1,000 patients have now been involved.

Our evidence points towards the ReSPECT process being superior to existing DNACPR documentation. It prompts conversations which may not have otherwise taken place, and ensures appropriate planning is in place in the event of a health crisis.

We also found that:

- 100% of key individuals were involved in decision making
- all patients and families rated the process positively

What should happen to you in an emergency?

What is it?
The ReSPECT process creates personalised recommendations for your clinical care in emergency situations in which you are not able to decide for yourself or communicate your wishes.

Who is it for?
Anyone may have a ReSPECT form, but it will have increasing relevance for people who have particular needs; for those who are likely to be nearing the end of their lives; or for those who want to record their care and treatment preferences for any other reason.

Resources, such as the poster above, are available at www.resus.org.uk/respect

- patients with a ReSPECT form were more likely to still be at home three months after a hospital admission
- a more sustainable digital solution is required to support the project locally and nationally.

NHS Forth Valley is the first health board to use the ReSPECT process, generating great interest across Scotland and the rest of the UK. Further work is underway for an electronic ReSPECT form, which will be available as part of the NHS Scotland’s National Digital Platform.

To watch a video about the ReSPECT process, funded by Macmillan, go to nhsforthvalley.com/media-item/respect-for-treatment
End of life care
Resources

Macmillan (2019). At the crossroads: How can the NHS Long Term Plan improve end of life care in England?
This report is based on research and insight gathered from healthcare professionals working on the front line. Available at: www.macmillan.org.uk/crossroads (Accessed October 2019)

The NHS Long Term Plan has set the national direction of travel for the NHS in England for the next 10 years and outlines that end of life is a priority area for improving care. Available at: www.longtermplan.nhs.uk (Accessed October 2019)

End of life: A guide.
This Macmillan booklet provides information and support for what to expect and how to plan for the end of life. Available at: be.macmillan.org.uk/be/p-20885-end-of-life-a-guide.aspx

References
Have you got an idea for a future issue of Sharing good practice? Get in touch at macvoice@macmillan.org.uk