

Major Conditions Strategy Sue Ryder response

June 2023

How can we better support and provide treatment for people after a diagnosis?

Having conversations about palliative care and making plans for the end of life is an essential part of support for many people diagnosed with life limiting conditions. Planning for end of life can help to ensure that people can live as well as possible while living with potentially life-threatening illnesses. It is also important in helping people to deal with the uncertainties of a prognosis. This is key as prognostication can often be difficult for doctors, particularly for diseases other than cancer.

Conversations about palliative and end-of-life care (PEoLC) should be individualised and carried out when the patient is ready. Ideally these conversations should not be left until it is too late, for example when the patient is too ill to make decisions or be moved to a different location to be cared for. It must also be recognised that some may never want to have these conversations.

These conversations are key for those diagnosed with a number of major conditions. For example, it is recognised that PEoLC for people with dementia demands a shift from reactive care based on uncertain prognosis, to responsive care based on need.¹

However, the support offered through general practice can massively vary. A 2023 Kings Fund report found variation around issues such as *'engaging with end-of-life care as a priority, identifying patients approaching the end of life, capability and willingness to discuss end of life and advance care planning, use of Electronic Palliative Care Co-ordination System (EPaCCS), use of end-of-life care registers, referral rates to specialist palliative care, and monitoring arrangements within practices for the quality of end-of-life care.'*²

Advance Care Planning must be carried out for anyone who needs it. Advance Care Plans (ACPs) are relevant for anyone who wants to plan for their future care or who may be at increased risk of losing their mental capacity in the future.³ NICE has a [quick guide](#) on who may need an ACP and tips for having these conversations and creating the plan.

Despite the importance of ACP, too many do not have a plan in place. Sue Ryder polling from 2023 found that 86% of people in the UK have not written an ACP. **The strategy must emphasise the importance of planning ahead and include steps on how more people can make an ACP.** As part of this, DHSC must consider the touchpoints in people's lives where it's appropriate to educate individuals and have discussions around end-of-life care and bereavement, so that people are not considering these issues for the first time when they get a diagnosis of a life-limiting/threatening condition.

Day services, such as rehabilitation services and day hospice services are important in providing treatment and support. Many people will live with conditions for a long time and will rely on vital support in the community. Improving access to these services requires workforce planning, as well

¹ King's College London (2023), A right to be heard: Better palliative and end-of-life care for people affected by dementia. <https://www.kcl.ac.uk/nmpc/assets/a-right-to-be-heard-policy-brief.pdf>

² The King's Fund (2023), Dying well at home: Commissioning quality end-of-life care. <https://www.kingsfund.org.uk/sites/default/files/2023-02/dying-well-at-home-report.pdf>

³ <https://www.england.nhs.uk/wp-content/uploads/2022/03/universal-principles-for-advance-care-planning.pdf> (last accessed 23.06.23)

as a drive to ensure people are physically able to access services to receive ongoing support. Sue Ryder polling from 2023 found that, since April 2022, 60% of respondents at the end of life have been unable to attend medical or day centre therapy appointments due to increased costs. **To help address this, the strategy should include measures to ensure that there is the right infrastructure (such as access to free/subsidised travel and appropriate workforce provision) to allow people to access support after diagnosis.**

In addition, we support The Neurological Alliance's recommendations that, to improve support for people following diagnosis of a neurological condition:

- Shortages in the neurological workforce, which currently impact the effectiveness of treatment, care and support available, must be addressed.
- There is a need to better integrate and promote collaboration between services for people affected by neurological conditions and associated specialties.

How can we better enable health and social care teams to deliver person-centred and joined-up services?

Generalist Health Services

The proportion of people dying in the community has been increasing for at least two decades and is projected to continue, with deaths at home and in care homes overtaking the number of deaths in hospitals and hospices by the 2030s.⁴ If the number of deaths at home does continue to rise as expected, there will be even greater demand for person-centred PEOLC in the community. This demand will need to be met by both specialist hospice teams and generalist health services and will place even more importance on the delivery of joined-up care.

Recent research by the King's Fund found that commissioners of end-of-life care often had little or no data about generalist services in their area. And in some cases, commissioners shared that they had literally no quality measures for generalist end-of-life care at home.⁵ Such data is essential in supporting commissioners to build a complete picture of PEOLC provision in the community.

We support the King's Fund assertion that **commissioners need to focus on and plan for the critical role of generalist health services in enabling a good death at home**,⁶ and that **ICB leaders must help to facilitate this by including generalist health services within quality monitoring**.⁷

24/7 PEOLC

People with palliative or end-of-life care needs must be able to access 24/7 care to support pain and symptom management. However, there are significant gaps in the provision of 24/7 PEOLC support across the UK. For example, Marie Curie research from 2022 found that 27% of areas in the UK have no designated line for out of hours palliative and end-of-life care and 42% only had partial coverage.⁸

⁴ The King's Fund (2023), Dying well at home: Commissioning quality end-of-life care.

<https://www.kingsfund.org.uk/sites/default/files/2023-02/dying-well-at-home-report.pdf>

⁵ Ibid.

⁶ Ibid.

⁷ The King's Fund (2023), Policy brief: How can ICBs improve end-of-life care for people who die at home?

<https://www.kingsfund.org.uk/sites/default/files/2023-02/dying-well-at-home-policy-brief.pdf>

⁸ Marie Curie (2022), The Better End of Life Report 2022. <https://www.mariecurie.org.uk/policy/better-end-of-life-2022>

The research also highlights the high frequency of visits to emergency departments for people at the end-of-life and that out of hours visits to emergency departments increase more than in hours visits in the last months of life.⁹ This indicates that better provision of 24/7 PEOLC services in community settings could alleviate pressures on emergency departments.

The importance of 24/7 PEOLC services is recognised by NHS England in the PEOLC statutory guidance for Integrated Care Boards (ICBS). The guidance outlines the need for ICBS to “engage in defining how their services will operate population needs 24/7”.

To support the delivery of person-centred care, ICBS must address shortcomings in 24/7 access to PEOLC when planning and commissioning services for their local populations. In doing so, ICBS should adhere to NHS England’s good practice guidance, which states that 24/7 face-to-face PEOLC services should be “coordinated with other care teams who have contact with the person e.g., community nursing, district nursing and personal assistants”.¹⁰

As well as facilitating better pain and symptom management for people with PEOLC needs in the community, this can in turn help to alleviate the chronic pressures on emergency services.

In addition, **the Major Conditions Strategy should consider how family and friends can be better equipped to provide support for people with palliative or end-of-life care needs, where appropriate.** When patients are in hospital, nurses spend about 5% of their time in face-to-face interactions with patients and doctors spend only about 13–15 minutes a day in contact with an individual patient. The time spent with patients dying at home is even less. This situation has been termed the 95% rule, meaning that 95% of the care of the dying is undertaken by lay communities despite the dominance of health-care systems.¹¹

Workforce planning

Charitable hospices are the main providers of specialist palliative and end-of-life care in the UK, supporting 300,000 people every year across all settings.¹² However, the deepening workforce crisis within the hospice sector threatens the provision of PEOLC services both now and in the future.

Hospices face unique recruitment and retention challenges. Systemic problems affecting the wider health and care sector workforce are compounded by the lack of adequate statutory funding, which impacts the hospice sector’s ability to keep pace with NHS pay. UK hospices would need to raise an additional £120 million pounds a year to match the recently announced increased pay awards for NHS nurses and other staff.¹³

Other drivers of workforce shortages within the hospice sector include the ageing workforce, an insufficient pipeline of palliative and end-of-life care professionals, unequal access to training and

⁹ Ibid.

¹⁰ [24/7 Care and Specialist Advice for Palliative and End of Life Care: Commissioner’s good practice guide](#) (last accessed 23.06.23)

¹¹ The Lancet Commission (2022), The value of death: bringing death back into life.

[https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(21\)02314-X/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(21)02314-X/fulltext)

¹² Hospice UK and Nuffield Trust (2022), Support at the end of life: The role of hospice services across the UK.

<https://www.nuffieldtrust.org.uk/sites/default/files/2022-06/hospice-services-web-1-.pdf>

¹³ <https://www.itv.com/news/2023-03-31/uk-hospices-face-funding-crisis-and-need-extra-120m-to-pay-staff>

education opportunities in comparison to NHS colleagues and burn out due to the psychological and emotional impact of the work.

Government must ensure an adequate supply of a skilled palliative and end-of-life care workforce in all settings and plan for the workforce as a whole system across health and social care, including for charitable providers of essential services.

Failure to ensure a sufficient supply of skilled staff within the hospice sector will ultimately impact the amount of care that hospices can provide against the backdrop of growing demand for specialist PEoLC.¹⁴ This will mean that patients and their families lose out on the person-centred support that hospices offer and result in increased demand on the NHS.

Funding considerations should be central to hospice sector workforce planning. A sustainable funding solution is desperately needed to enable the hospice sector to attract and retain a workforce which can meet growing need.

For people living with neurological conditions, **we support recommendations proposed by The Neurological Alliance around the delivery of person-centred and joined-up care, including:**

- The establishment of a lead for services for people affected by neurological conditions in every Integrated Care System (ICS).
- Ensuring every person with a neurological condition discusses and agrees a comprehensive care plan which includes their treatment and support, and voluntary sector services available to them in their community. The plan should be agreed using a shared decision-making approach.

How can we make better use of research, data and digital technologies to improve outcomes for people with, or at risk of developing, the major conditions?

Data

A national core data set should be developed for PEoLC, specifying the data that services and providers must collect and report to the ICS. This would enable better planning of services to meet local needs, facilitate greater integration and support both providers and central bodies to compare information and better understand the national picture.

Diversity data is key to an ICS understanding its PEoLC population health needs and in turn addressing inequalities and gaps in provision. However, collation of this information is currently inconsistent across different providers and data collection in PEoLC needs to improve. Research has found that family support, religious beliefs, homelessness, living with dementia or a learning disability and LGBTQ+ identity are all factors that contribute towards inequalities in access to PEoLC.¹⁵ ¹⁶ Better data collection on conditions is also needed, particularly co-existing conditions, to allow for better planning and delivery of care.

¹⁴ Sue Ryder (2021), Modelling demand and costs for palliative care services in England.

https://www.sueryder.org/sites/default/files/2021-03/Modelling_Demand_and_Costs_for_Palliative_Care_Services_in_England%20%281%29.pdf

¹⁵ Tobin J, Rogers A, Winterburn I, et al. (2022), Hospice care access inequalities: a systematic review and narrative synthesis. *BMJ Supportive & Palliative Care*. <https://spcare.bmj.com/content/12/2/142>

¹⁶ The King's Fund (2023), Dying well at home: Commissioning quality end-of-life care. <https://www.kingsfund.org.uk/sites/default/files/2023-02/dying-well-at-home-report.pdf>

In addition, **we support The Neurological Alliance’s recommendation that data collection should increasingly include outcomes (including, crucially, Patient Reported Experiences and Outcomes) rather than mainly focusing on inputs and processes.** Data held by NHS England (including NHSE regions) about performance within an ICS, including benchmarking with other providers and systems, should be available to the ICS itself and national government.

Technology

Virtual wards can be a good way of using digital technologies to care for people. There is a drive towards virtual wards within the NHS, with all ICSs being asked to extend or introduce virtual ward models. Supporting information for ICS leads states that, ‘In doing so, additional ‘bed’ capacity could be created as a result of efficient and productive use of resource and management of patients.’¹⁷

Sue Ryder carried out a virtual ward pilot at Wheatfields and Duchess of Kent hospices. The aim of the pilot was to provide a responsive, enhanced multi-disciplinary specialist palliative care service to manage complex and acute needs in the community, for patients felt to be at high-risk of inpatient admission. The virtual ward enabled patients to have complex symptom management, therapy reviews and psychosocial support in their place of choice, as well as avoiding unnecessary admissions to hospital or hospice.

In addition to improved patient outcomes, the pilot has shown that virtual wards effectively use technology to help to manage the increasing demand on palliative care services and share limited staff resourcing effectively. However, the efficiency of the model relies on collaboration across providers. Whilst a virtual ward can be delivered by a single provider, we believe it is more effective when hospice providers and NHS community teams work together. The model also relies upon the availability of skilled, multi-disciplinary staff, meaning that workforce shortages are a substantial barrier to the operation of virtual wards.

Research

More research needs to be carried out into PEoLC as the evidence base is currently underdeveloped. A 2022 scoping exercise carried out by the Social Care Institute for Excellence found that within PEoLC there ‘are significant gaps in the research necessary to support improvements in clinical practice, service model design, patient experiences and care outcomes.’¹⁸ It found that research is hindered due to limited resources and research infrastructure and that knowledge translation activities are not prevalent and are often not well coordinated across the sector.

¹⁷ NHS England and NHS Improvement (2022). Supporting information for ICS leads: Enablers for Success: virtual wards including hospital at home. <https://www.england.nhs.uk/publication/enablers-for-success-virtual-wards/>

¹⁸ <https://www.scie.org.uk/files/transforming-care/evidence-centre-palliative-end-of-life-care/peolc-evidence-centre-workshop.pdf> (last accessed 23.06.23)

Compared to many other sectors, PEoLC research is underfunded. Analysis found that of the £503 million spent on cancer research in 2013 in the UK, just £3.08 million (0.61%) was spent on PEoLC research.¹⁹

How can we improve access to palliative and end of life care?

Awareness and understanding of PEoLC

Research has found that public understanding of and awareness around palliative care is low.

An evidence review published in the British Medical Journal in 2021 found that more than half of patients did not have any information about palliative care or hospice care.²⁰ Patients had limited information about pastoral care, social care and bereavement care and patients' awareness about individuals or centres providing palliative care or hospice care was also limited.

Further, a 2021 study on public knowledge, attitudes and perceptions towards palliative care found that there are a range of knowledge gaps and misconceptions.²¹ It also found that a reluctance to have taboo conversations around death and dying may deter people from accessing integrated palliative care services earlier on.

Greater public awareness around what PEoLC is and when it can be accessed would support more people to get the right support at the right time. This would relieve pressure on the NHS, both in hospitals and in the community, where care can be delivered by specialist palliative teams.

Addressing inequalities

Many people are not able to access the help they need in their final days, months, and years, with inequalities in access to and standards of care particularly felt by those who have already encountered discrimination and unfairness throughout their lives.²² Research has shown that patients without cancer, the oldest, ethnic minorities and those living in rural or deprived areas are particularly under-represented in hospices.²³

The introduction of ICSs as statutory bodies in England has presented a significant opportunity to address these inequalities, as ICBs are legally required to commission PEoLC services which meet the needs of their local populations. However, whilst commissioners may recognise the importance of addressing inequalities in end-of-life care, many have not begun to take steps to reduce them.²⁴

Through research and outreach across the palliative and end-of-life care sector, progress has been made in understanding and overcoming the inequalities that some population groups face. **But**

¹⁹ <https://www.ncri.org.uk/new-report-highlights-low-levels-of-palliative-and-end-of-life-care-research-funding-in-the-uk/>

²⁰ Masoud B, Imane B, Naiire S (2021). Patient awareness of palliative care: systematic review. *BMJ Supportive & Palliative Care*. <https://spcare.bmj.com/content/early/2021/10/10/bmjspcare-2021-003072>

²¹ McIlpatrick, S., Slater, P., Beck, E. et al (2021). Examining public knowledge, attitudes and perceptions towards palliative care: a mixed method sequential study. *BMC Palliat Care*. <https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-021-00730-5>

²² <https://www.hospiceuk.org/our-campaigns/policy-and-influencing/influencing-parliamentarians/promoting-equality-end-life-care>

²³ Tobin J, Rogers A, Winterburn I, et al. (2022), Hospice care access inequalities: a systematic review and narrative synthesis. *BMJ Supportive & Palliative Care*. <https://spcare.bmj.com/content/12/2/142>

²⁴ The King's Fund (2023), Dying well at home: Commissioning quality end-of-life care. <https://www.kingsfund.org.uk/sites/default/files/2023-02/dying-well-at-home-report.pdf>

continued commitment from Government is needed if we are to truly eradicate inequalities in access to PEOLC. This should include the introduction of:

- An effective mechanism for holding ICBs to account if they don't act upon population health insights and commission services that will help to reduce inequality.
- A sustainable funding settlement for the hospice sector that delivers the stability that is needed to improve services for those who currently face the greatest barriers and encourages innovation to meet diverse population needs.

Dementia

There is an urgent need to improve access and availability of PEOLC for people with dementia. While palliative care needs in England and Wales are expected to increase, the greatest rise is projected to be among people with dementia. Despite this, there are persistent barriers to accessing palliative care for people with dementia.²⁵

Usually, people with dementia usually only need generalist PEOLC, unless there is complexity (such as ethical decision making or the prevalence of another condition). In such scenarios, specialist PEOLC may be required. The projected rise in palliative care needs for people with dementia encompasses both generalist and specialist PEOLC, however, **the Major Conditions Strategy should consider the PEOLC needs of people with dementia in the context of the ageing population.**

Multimorbidity increases with age, which is particularly relevant because far more deaths are projected to occur at older ages by 2040. This means that the complexity of palliative care need is likely to grow due to the high symptom burden, complex healthcare needs, and high hospitalisation rates of patients with multimorbidity.²⁶

A palliative care approach focuses on person-centredness, quality of life and dignity, autonomy, needs-based care, coordination and continuity of care. These are fundamental to supporting people affected with dementia, at any stage of the condition.²⁷ There is also increasing evidence that community palliative care can reduce emergency department attendance among people with dementia approaching the end of life.²⁸

We support the call for equitable access to integrated palliative dementia care, put forward by King's College London in their report 'A right to be heard: Better palliative and end-of-life care for people affected by dementia'. The report recommends that this is achieved through:

- Dementia Care Pathway to include access to an integrated palliative care approach, at any stage of dementia.

²⁵ King's College London (2023), A right to be heard: Better palliative and end-of-life care for people affected by dementia. <https://www.kcl.ac.uk/nmpc/assets/a-right-to-be-heard-policy-brief.pdf>

²⁶ Etkind, S.N., Bone, A.E., Gomes, B. et al. (2017), How many people will need palliative care in 2040? Past trends, future projections and implications for services. BMC Med 15, 102 (2017). <https://bmcmmedicine.biomedcentral.com/articles/10.1186/s12916-017-0860-2>

²⁷ King's College London (2023), A right to be heard: Better palliative and end-of-life care for people affected by dementia. <https://www.kcl.ac.uk/nmpc/assets/a-right-to-be-heard-policy-brief.pdf>

²⁸ Ibid.

- Integrated Care Boards to consider dementia in fulfilling their legal duty to respond to palliative and end-of-life care needs of the local population.

We also support recommendations put forward by the Neurological Alliance that:

- Core multidisciplinary teams (MDTs) should include palliative care. For many conditions, early palliative care (not just at the end-of-life) should be provided.

How can we better support those with mental ill health?

Millions of people face bereavement every year in the UK, but many do not get the support they need. This can worsen mental health and, in some cases, lead to long term mental ill-health.

Sue Ryder's research '*A better route through grief: Support for people facing grief across the UK*' found that 70% of respondents who had experienced a close bereavement said that they could not access the support they would have liked.²⁹ The most common types of formal support that people wanted but could not access were counselling (28%), financial support (28%), written information (25%) and mentoring/befriending (24%).

In order to improve access to bereavement support, bereavement services and mental health services need to be far more integrated. Currently, mental health services, such as IAPT (Improving Access to Psychological Therapies) services, will often signpost people experiencing grief to an organisation that provides specific bereavement support, such as Sue Ryder or Cruse. While we support the signposting of individuals to third sector providers, NHS mental health providers should also be able to effectively support people experiencing poor mental health as a result of grief and bereavement. Certain people will need to receive mental health support from the NHS due to the severity of their mental health needs, and will also need bereavement support. Bereavement specific organisations may not be able to support these individuals. For example, Sue Ryder has not been able to accept certain people into our online Bereavement Counselling Services as they were presenting with severe mental health issues such as very recent suicide attempts (i.e. in the previous week), or had a very recent mental health inpatient stay.

Therefore, when it comes to supporting the wellbeing of people who are facing bereavement there needs to be better integration of public services. Public services need to be able to signpost and refer users to the correct local services.

A key barrier to achieving this is that there is no set commissioning pathway for bereaved people who need support. Therefore, health and care professionals such as GPs do not always know the correct place to signpost and refer to, meaning that many people are not getting the right support and there are large variations in the support that is being offered. Sue Ryder polling of GPs in 2022 found that GPs from across the UK spoke about the negative impact of not having a pathway to support. Most GPs we engaged with identified 2-3 key services that they signposted individuals to, and many said that they did not know of services beyond these main options.

Furthermore, there is currently a lack of clarity on how to provide the right support, at the right level for those who are bereaved and have Prolonged Grief Disorder. Those accessing level 3 mental health services may need a level 4 service but there can be issues in referring between the services. There needs to be more clarity on how and when to make this referral. Additionally, for those that

²⁹ Sue Ryder (2022), A better route through grief: Support for people facing grief across the UK.

<https://www.sueryder.org/sites/default/files/2022-06/A%20better%20route%20through%20grief%20report.pdf>

may receive or need care at different levels, it needs to be ensured that there is ongoing and efficient communication between services regarding the individual's care and treatment pathway so that they get the right level of care and don't end up on missing out on care entirely as different services aren't communicating.

In light of **this the Government must support the development of a bereavement specific pathway that adopts a public health approach**. The pathway should be informed by evidence of effective clinical and non-clinical interventions and should establish formal referral partnerships and feedback loops. It should draw on the expertise of organisations who support people through bereavement and be co-created with people with lived experience. Bereavement services should be able to inform and equip NHS mental health services. NHS services should learn from bereavement services to improve the bereavement support they can provide. Better integration and communication between bereavement services and NHS mental health services would mean that more people would be able to get high quality support for both bereavement and poor mental health. This is particularly important for those with more complex mental health needs.

In addition, we support recommendations put forward by The Neurological Alliance on the improvement of mental health support for people living with neurological conditions.