Delivering Core NHS and Care Services during the Pandemic and Beyond

Sue Ryder evidence to the Health and Social Care Select Committee
8 May 2020
Summary

Sue Ryder and the people we provide care for have been greatly affected by Covid-19 in a number of ways. In response we have:

- Supported the NHS by assisting it to free up hospital beds so that people with Covid-19 can be admitted to hospital;
- Expanded our use of technology to more flexibly provide care and support without necessarily requiring face-to-face interventions; and
- Experienced some very positive ways of working with the NHS and others in a flexible way to meet the needs of the people we provide care for.

What should happen next:

- In the short term, the NHS must find ways to refer and treat people with life threatening conditions who are currently unable/feel unable to access the care they need;
- The NHS and social care must work together to reinstate community services designed to keep people living as independently for as long as possible;
- The rehabilitation pathway for people with neurological conditions should be opened up to allow people to move from hospital to home wherever possible, and fulfil their potential;
- Government must work with the palliative care sector to ensure the system is geared up to meet the anticipated growth in need for palliative care in the aftermath of the current crisis;
- The NHS should work with specialist palliative care providers to respond to need and put in place extended hours palliative care and bereavement support via phone or online to professionals and/or the public;
- Government should ensure that the growing need for bereavement support that will arise from this crisis is addressed in a range of flexible ways that meet people’s needs; and
- Government should reform the way in which palliative care is commissioned and funded by the NHS.

On 8 April 2020, the Treasury announced a very welcome package of financial support for the hospice sector which will go a significant way to offsetting the drop in income we and other palliative care providers are experiencing as a result of the Covid-19 crisis. This means that we will be able to continue to provide care over the coming months but we do not know what the medium to long term looks like. Covid-19 represents an opportunity for government to work with experts like ourselves to reform the way palliative care is provided, to end the reliance on the goodwill of the public to ensure people who need palliative care get it, and to start providing it in a way that meets people’s needs, i.e., wherever possible in the community and people’s homes, rather than hospice inpatient units.

Sue Ryder

Sue Ryder supports people through the most difficult times of their lives. For over 65 years our doctors, nurses and carers have given people the compassionate and expert care they need to help them live the best life they possibly can. We take the time to understand what’s important to people and give them choice and control over their care. We see a future where our palliative and neurological care reaches more communities; where we can help more
people begin to cope with bereavement; and where everyone can access the quality care they deserve.

Across the UK we have six hospices and associated community palliative care services, one standalone community palliative care service and four specialist neurological centres. We also provide bereavement support via our Online Bereavement Community and Online Bereavement Counselling, in addition to that provided by our family support teams in our hospices.

The people we provide care for are deeply affected by the Covid-19 crisis and the services we provide have adapted in response. For instance, we have worked with our local NHS colleagues to ensure we could provide care for people in our hospices who would not normally receive specialist palliative care, in order to free up hospital beds for people with Covid-19. We have expanded our capacity to carry out consultations with our service users remotely. We have made changes to how we provide care to residents in our neurological centres as many are classed as extremely vulnerable, requiring shielding. We’ve also seen demand for our bereavement counselling service grow so have responded to that demand, and provided advice and support in response to Covid-related issues through our online community.

This response sets out our experiences with regard to the questions posed by the Health and Social Care Committee Inquiry, and sets out where we believe priority should be placed in relation to the future of palliative care, neurological care and bereavement support.

Response

How to achieve an appropriate balance between coronavirus and ‘ordinary’ health and care demand; Meeting the wave of pent-up demand for health and care services that have been delayed due to the coronavirus outbreak

As the NHS starts to consider how it can resume certain services depending on local circumstances, the needs of people who may have terminal conditions need to be considered. For instance there is evidence\(^1\) that people are less likely to attend A&E as readily as they would normally when experiencing heart problems or stroke. Similarly, people who may have cancer are experiencing delays in referrals\(^2\) resulting in a knock-on effect on diagnosis and treatment and ultimately life expectancy. Indeed, some of our palliative care services are

\(^1\) Figures suggest ½ the number of people will go to A&E departments in hospitals in England in April, compared with April 2019 - down to just over 1m visits. Experts are concerned people are not getting potentially life-saving treatment for heart attacks and strokes, with a 50% fall in the number of people seeking medical help for heart symptoms. [https://www.bbc.co.uk/news/health-52417599](https://www.bbc.co.uk/news/health-52417599) Accessed 06 May 2020

\(^2\) Overall, the number of urgent referrals has dropped to around 25% of usual levels in England. For every week the pandemic continues, over 2,300 cancer cases are likely to be going undiagnosed across the UK. Research from Cancer Research UK [https://scienceblog.cancerresearchuk.org/2020/04/21/how-coronavirus-is-impacting-cancer-services-in-the-uk/](https://scienceblog.cancerresearchuk.org/2020/04/21/how-coronavirus-is-impacting-cancer-services-in-the-uk/)
finding that the time between people being referred to us and subsequently dying is much shorter than usual, reflecting the trend for people to wait much longer for medical intervention.

People living at home with degenerative neurological conditions such as multiple sclerosis or Huntington’s Disease may have had their normal services withdrawn or cut back, meaning they find it more difficult to manage their condition which can lead to hospital admissions and more complicated problems further down the line. This may well result in an increase in the level of care required both in terms of complexity and intensity, affecting the person’s quality of life as well as overall health and wellbeing.

Local health systems must put in place processes that allow people with potentially life threatening conditions to access the care they need more rapidly as soon as it is safe to do so. The delays in diagnoses and treatment may be expected to result in an increase in palliative care needs and death rates over the coming months and years – as the rising death rate figures in March[^3] seemed to indicate – so palliative care pathways including access to the specialist care and support provided by organisations such as Sue Ryder must be clear and geared up to meet this need.

As a provider of intensive rehabilitation for people with neurological conditions such as brain injury or stroke, we are aware that there are often blockages in the system that mean when we are ready to discharge people they cannot move home or into suitable accommodation because of a lack of community rehabilitation services. However that problem has become even more common since the start of the Covid-19 outbreak, in part due to the redeployment of rehabilitation staff to different roles to help support the NHS response. This has highlighted the urgent need for leaders in the health and care system to start considering the services people need in their entirety, and ensuring that one part of the system supports another: no-one should be discharged from hospital only to find the care and support they need in the community is not available.

**Meeting extra demand for mental health services as a result of the societal and economic impacts of lockdown**

Sue Ryder provides online bereavement support via our Online Bereavement Community and Online Bereavement Counselling. Covid-19 has had a significant impact on the people using these services – whether directly in relation to the virus itself or indirectly in relation to how they are able to cope during such difficult circumstances – and we have adapted our services in response. For instance we’re experiencing a significant increase in the volume of people seeking bereavement counselling and are recruiting additional counsellors to meet this demand. In our Online Bereavement Community we’ve updated the information resources to reflect the changes in services available, such as funerals and registering a death. We’ve also updated safeguarding processes and signposting processes given the nature of all the

[^3]: 90,392 deaths from all causes were registered in England and Wales from the week ending March 27 to the week ending April 17, up from 39,039 for the same three week period in 2019, Office for National Statistics [https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datalist](https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datalist) Accessed 06 May 2020
changes that have occurred. In April we experienced the highest ever number of posts in the community including a high volume of posts about coronavirus, mainly focused on the following themes:

- General anxiety about the virus and risk to loved ones
- The impact of lockdown and isolation on their grief (not being able to see friends and family, attend counselling or support groups etc)
- Recent bereavements where funerals have been affected by lockdown rules
- Not being able to visit ill and vulnerable relatives, including those receiving end of life care.

Some of our hospices have also been asked by CCGs locally to provide specifically Covid-related bereavement support via phone on a temporary basis since the crisis unfolded. However we're keen to see this kind of support available to anyone regardless of location, particularly as we anticipate the impact of Covid-19 and the lockdown on people's ability to grieve will be felt for many years to come.

For people with neurological conditions, specialist neurological psychological support is acknowledged as a critical part of the care pathway, yet is generally very difficult to access. However it's now virtually impossible to access. In addition to this lack of specialist support, the mental wellbeing of people with neurological conditions who often already feel isolated will be suffering even further as a result of the lockdown and need for self-isolation. The impact on the mental wellbeing of family carers is likely to be profound.

Meeting the needs of rapidly discharged hospital patients with a higher level of complexity

Our experience of working with our local CCGs to help cope with Covid-19 has largely been very positive. It has shown that in a time of crisis the system can adapt quickly and this means that in some cases we have provided care for people we would not ordinarily support in our palliative services. For instance some of our hospices are working more closely with care homes to support their residents at the end of life due to Covid-19, prisons, and with mental health services.

In some cases we have experienced an increase in hospitals discharging people on a Friday without the adequate care package in place or without anticipatory care drugs for people at the end of life, and our hospice community teams have stepped in to try to mitigate the problems that have arisen. However other areas are involving our hospices in ‘Hospital Patients Medically Fit for Discharge’ meetings which have been much more successful in ensuring people get the care they need in the right place.

Sue Ryder Neurological Care Centre The Chantry, in Suffolk, provides specialist neurological rehabilitation and in response to a request from the CCG, with whom we work closely, we adapted our rehab model to allow us to care for more people than usual whilst maintaining appropriate infection control measures. Again, this goes to show how quickly the system can adapt when time is short.

Providing healthcare to vulnerable groups who are shielding
Some of the people who live in our neurological centres belong to groups required to ‘shield’ due to other health conditions. While we have introduced barrier nursing to ensure they are appropriately protected, this is very difficult for the clients concerned and staff as it impacts negatively on relationships. In addition, it is more difficult to provide personalised care in what is effectively someone’s home. So while we understand the need to take this approach, this is not something we’d like to continue to do indefinitely.

Within our community services, it is only possible to care for people who are shielding if our staff have the correct PPE. Sadly, despite efforts by all concerned, this is an ongoing issue for the social care and hospice sector and while we have some PPE at this point in time, we do not have access to a regular, reliable source of PPE.

Supporting mass testing and vaccination once they become available

Sue Ryder has been asking for support for testing for staff and the people who use our services as we see this as vitally important to being able to maintain our services. We will be supportive of mass testing and vaccination as the groups of people we provide care for would often be amongst the most vulnerable to Covid-19 as well as being most severely impacted by the restrictions that have resulted from the crisis.

How to ensure that positive changes that have taken place in health and social care as a result of the pandemic are not lost as services normalise

**Palliative care**

As the crisis has developed, we’ve experienced a decline in use of our inpatient units at our hospices as people have preferred to stay at home for a range of reasons relating to Covid-19, and because of a lower referral rate due to cessation of some cancer services. In some areas we have experienced an increase in our community services such as Hospice at Home, and a greater use of technology to allow remote consultations and advice without people travelling to the hospice, or staff to people’s homes. In this regard the crisis seems to have accelerated a trend that was already happening, i.e. people preferring to receive personalised palliative care at home where possible. While this is a model we have been striving towards for some time, and have set up a number of smaller scale community services, it is a model that CCGs are sometimes reluctant to explore further, still less start to commission. As such we hope that this experience has persuaded some CCGs of the case for designing palliative care services around the needs of people who use them rather than the easier to quantify hospice beds-based model. This will require some flexibility and better joint working, but Covid-19 has shown this to be possible.

This experience has not only demonstrated that the way we provide palliative care must change, but has also laid bare how inequitable and unsustainable the funding situation is. We are grateful that the Treasury is stepping in to offset some of the drop in income we and other palliative care providers are experiencing as a result of the lockdown. It is clear that our services are valued and absolutely critical to good quality care, yet for historical reasons the sector relies on the goodwill of the public to fund most of the services we provide. As a result we have regular negotiations with commissioners regarding funding which are about a fight for survival rather than strategic planning to meet the current and future needs of local
populations. Covid-19 represents an opportunity to review how funding is allocated, alongside how services are commissioned, with a view to placing the sector on a sustainable footing so it can continue to provide its much needed services, as part of the wider health and social care sector.

As highlighted above, some of our hospices have also been asked by CCGs locally to provide specific Covid-related bereavement support via the phone, and others are now providing palliative care advice and support to other healthcare professionals on an extended hours phone service. Along with palliative care support and advice, this highlights a need for 24/7 support regardless of Covid, so we do hope that this leads to a step change in CCGs’ approach to commissioning 24/7 telephone/digital triage and advice palliative and bereavement support services.

The rapidly increased use of digital technology to allow remote consultations in both palliative care and neurological care shows just how much potential this area has, and is something we are keen to expand further where it meets the needs of the people using the services.

**Neurological care**

The clear need for specialist rehabilitation for people with neurological conditions has been demonstrated by the current crisis. Sue Ryder Neurological Care Centre The Chantry in Suffolk normally provides on-site rehabilitation for up to twelve weeks from a team of physiotherapists, occupational therapists, speech and language therapists, a neuro-psychologist, nurses and rehabilitation assistants to support clients to build strength and develop skills for more independent living. This service has been commissioned on a spot-purchase basis to date but is now provided on a block purchase basis for shorter, more intense rehabilitation treatment for people being discharged from hospital. This was because of the need for hospital beds for people with Covid-19 and because therapists in community services were being redeployed.

We have risen to the challenge and provided the rehabilitation that has been required demonstrating how valuable it is both for clients and for the NHS as it tries to free up beds. However, as we experienced before Covid-19, our clients are sometimes ready to move onto more independent living, often in their own homes, but their support packages and the further community rehabilitation needed are not available. So this area of the pathway must be addressed to allow people to fulfil their goals and live as independently as possible.

We believe one of the areas of healthcare requiring the most attention and investment after Covid-19 will be community rehabilitation, and planning must take place now to ensure rehabilitation pathways are open for all, regardless of the level of specialist input required.

**Bereavement support**

An increase in death rates as a result of Covid-19, and an increase in public discourse about death and dying has resulted in a better understanding of the need for support when grieving. This is an area in which Sue Ryder has considerable experience via our Family Support Teams at our hospices, our Online Bereavement Community and our Online Bereavement Counselling. We believe that there needs to be more cultural openness about death and dying
and that access to various different types of bereavement support should be available to all who might need them.

Around 11% of people are likely to suffer ‘complicated’ or ‘prolonged’ grief following a death from natural causes; rates are likely to be higher following a traumatic death.\(^4\) Deaths from the coronavirus outbreak are being considered ‘traumatic’ given the situations in which people are dying, and the wider contextual situation in which people are grieving, meaning we can expect this number to be higher in current circumstances. Yet, assuming just 11% of people who have been bereaved want or need bereavement support, this already equals almost 50,000 people since lockdown began.\(^5\) This number will continue to rise, and the NHS and leading bereavement support services do not have the capacity to meet this demand. Prior to the pandemic, less than half of bereaved people in the annual VOICES survey who wanted to talk to someone from health, social care or a bereavement service about their grief were able to do so.\(^6\) Limited catchment areas, long journey times, waiting lists and limited provision all preclude access to support. Even where services are available, people may not know about them, or may feel stigmatised by seeking support. Clearly, there is a significant gap in this area and we hope that the spotlight shone on this area due to Covid-19 results in a cultural shift in our society and in the support that is made available for people who are bereaved.


\(^5\) 90,392 deaths from all causes were registered in England and Wales from the week ending March 27 to the week ending April 17 (ONS). Assuming that each death leaves an average of 5 people bereaved, this equates to 451,960 people coping with loss. And 11% of this total is 49,716 people. [https://www.mariecurie.org.uk/media/press-releases/marie-curie-launches-national-bereavement-support-service/274722](https://www.mariecurie.org.uk/media/press-releases/marie-curie-launches-national-bereavement-support-service/274722) Accessed 06 May 2020