Marie Curie response

Inquiry into the impact of COVID-19 on care homes

Care and support through terminal illness

ABOUT MARIE CURIE

1. Marie Curie is a leader in the provision of care and support to people affected by terminal illnesses in Northern Ireland. We provide a range of services including the Marie Curie hospice in Belfast, Nursing Service and Helper Service. Last year we provided care and support for over 4,500 people living with a terminal illness, their carers and loved ones.

2. We welcome the opportunity to respond to the Health Committee's inquiry into the impact of COVID-19 on care homes in Northern Ireland. The terms of the reference for the inquiry cover a wide range of important issues and challenges, but we have only provided responses to those areas for which we believe we can make a meaningful contribution based on our experience and expertise.

MEDICAL CARE WITHIN CARE HOMES

3. The COVID-19 pandemic has underlined the urgency of ensuring greater palliative and end of life care in-reach to care homes in Northern Ireland, including both medical and nursing care. Up to the week ending 9 October, nearly 440 COVID-19 deaths were registered among local care home residents, [1] and palliative care can and should have played a critical role in the care and support provided to all of these patients as they reached the end of life.

4. Palliative care has been shown to play an important part in managing the distressing symptoms of COVID-19, including breathlessness, agitation and anxiety. A palliative approach can also help to facilitate future care planning (see more below), communication with COVID-19 patients and their families, and grief and bereavement support for those loved ones left behind. [2] As an April editorial in *The Lancet* medical journal states: "palliative care ought to be an explicit part of national and international response plans for COVID-19." [3]

5. Since the COVID-19 outbreak began in Northern Ireland, Marie Curie's nursing service has provided increased levels of support for local care homes – for residents both with and without Coronavirus. We believe this reflects the increasing palliative care needs in care homes over the course of the pandemic mixed with heighted workforce pressures in the sector.

6. Even before the COVID-19 pandemic began, it was clear that some local care homes needed greater palliative and end of life care support. This was hinted at by the Minister for Health when he announced plans for a new framework for nursing, medical and multidisciplinary in-reach into care homes on 17 June; outlining the case for the new framework, the Minister said: "there has been an important shift in the complexity of care provided in care homes over recent years… Residents who would have been in hospital five years ago and receiving palliative or end of life care are often now cared for in nursing and residential homes." [4]

7. Providing an update on the development of the in-reach framework, the Department's COVID-19 Surge Planning Strategic Framework states that the work will be developed in partnership with care home providers, HSC Trusts, voluntary and community sector, clients and their families and the staff who provide the care. [5] It is currently unclear, however, who these stakeholders are; whether they include stakeholders with expertise in palliative and end of life care; or whether community and voluntary

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[1] Northern Ireland Statistics and Research Agency (2020). Weekly deaths.
[2] Ting, R et al (2020). Palliative care for patients with severe COVID-19. *BMJ*, 370.
[3] Editorial: Palliative care and the COVID-19 pandemic. *The Lancet*, 395 (10231).
[4] Department of Health. New framework planned for nursing and medical input to care homes.
[5] Department of Health (2020). COVID-19 surge planning strategic framework.

sector palliative and end of life care providers have or will be part of the project. It is important that these points are clarified.

8. Marie Curie believes that palliative care in-reach support needs to be responsive whenever care homes ask for help, and dependent only on the existence of palliative care needs among residents – not the intensity of these needs or adherence to a false dichotomy of 'generalist' vs 'specialist' palliative care.

9. Marie Curie is currently engaging with the care home sector in Northern Ireland to assess the palliative and end of life support needed by providers. We hope this exercise will identify the areas of need – be they direct in-reach, education, training (see further below) and/or something else – and shape our future offering to the sector under a co-designed approach.

Recommendations

- Clarity should be provided on the involvement of palliative and end of life care stakeholders, including those from the community and voluntary sector, in the development of the Department of Health's new framework for nursing, medical and multidisciplinary in-reach into care homes.

STAFFING LEVELS, TRAINING AND GUIDANCE

10. Linked to the section above, the COVID-19 pandemic has further exposed long-standing issues with the levels of training and experience in palliative care in some care homes in Northern Ireland. Many care homes provide excellent palliative and end of live care for their residents, but this is not universal and where gaps do exist, the root of the problem tends to be structural – with high staff turnover, inadequate staffing levels and lack of access to training due to time pressures and funding issues all making it difficult to equip care home staff with the skills they need to provide complex care to dying residents.

11. While COVID-19 has highlighted these issues, they existed for a long time before the pandemic. Planning for any further waves of COVID-19, as well as the longer-term process of reforming adult social care in Northern Ireland, must therefore include urgent measures to deliver greater levels of training, education and upskilling in palliative and end of life care among care home staff. Importantly, this should recognise the fragmented nature of the care home sector in Northern Ireland, where different levels of palliative and end of life care training, education and competency exist across the wide range of providers, which vary significantly in terms of bed numbers and workforce size.

12. In this context, it is concerning that neither the final report of the Rapid Learning Initiative into COVID-19 and care homes, nor the COVID-19 Pandemic Surge Planning Strategic Framework, makes any reference to actions to increase palliative and end of life care training, education or upskilling for local care home staff. While we appreciate that delivering this training and upskilling in a universal sense will not be an overnight project, these two papers provided an important opportunity to embed a public commitment to improve palliative care training in social care settings in Northern Ireland's future planning for COVID-19.

13. The Committee for Health will be well aware of the long-term challenges in securing the social care workforce that Northern Ireland needs – e.g. issues around pay, terms and conditions and career progression etc. – so we do not intend to rehearse them at length here. These issues existed for a long time before the COVID-19 pandemic began, which is why the root-and-branch reform promised under the Power to People report in 2017 is so important. As that report stated, "a low paid, high turnover and undervalued workforce is a poor way to ensure the quality of care we demand" [6] – a sentiment that applies equally to the present day as it did back in 2017.

14. Again, a quick fix does not exist, but it would seem impossible to have any meaningful conversation about how we can ensure the experienced and skilled care staff needed to respond to future waves of COVID-19 without acknowledging these problems as part of workforce planning.

[6] Expert Advisory Panel on Adult Care and Support (2017). Power to people: Proposals to reboot adult care and support in NI.

Recommendations

- Measures to deliver greater levels of palliative and end of life care training, education and upskilling to care home staff should be embedded in the Department of Health's future response plans for COVID-19.
- The challenges presented by low pay and poor terms and conditions in the care sector should be acknowledged and considered as part of workforce planning for future waves of COVID-19.

ADVANCE CARE PLANNING

15. The COVID-19 pandemic has highlighted the importance of advance care planning (ACP). ACP conversations allow patients and their loved ones to consider ceilings of treatment, issues such as resuscitation (see further below) and end of life preferences, including preferences around admission to hospital and place of death – all critical issues in the context of COVID-19.
16. At the same time, the pandemic has made initiating and recording these discussions more difficult in some cases. The following are just some of the additional COVID-related barriers to ACP in care homes:
    - Sensitive and compassionate consultation with care home residents and their loved ones about future care options is more challenging under social distancing measures and restrictions on in-person visiting.
    - The speed at which people with COVID-19 can deteriorate – especially if they are living with other complex comorbidities, as is the case with many care home residents – makes the timeliness of advance care planning conversations even more important. [7]
    - The pressure facing care home staff and reduced access to GPs for care home residents in the COVID context reduces the opportunities for ACP conversations.
    - Public trust and confidence in the ACP process may have been diminished by media stories in the early months of the outbreak which alleged that local patients were pressured to sign Do Not Resuscitate orders or had DNR or DNACPR orders put in place without consultation with them or their families.
17. These issues mean that all opportunities should be taken to have early, honest conversations about goals of care and treatment escalation in the care home setting. [8] Specifically, Marie Curie supports the approach to treatment and care planning in the context of COVID-19 in NICE guideline NG163, [9] which recommends the following:
    - When possible, discuss the risks, benefits and possible likely outcomes of the treatment options with patients with COVID-19, and their families and carers, so that they can express their preferences about their treatment and escalation plans. Use decision support tools (when available). Bear in mind that these discussions may need to take place remotely.
    - Put treatment escalation plans in place because patients with COVID-19 may deteriorate rapidly and need urgent hospital admission.
    - For patients with pre-existing advanced comorbidities, find out if they have advance care plans or advance decisions to refuse treatment, including do not attempt resuscitation decisions. Document this clearly and take account of these in planning care.
18. Beyond questions of timeliness, advance care planning has also been hamstrung in some cases by pre-existing structural barriers, specifically the lack of a regional system for recording ACP and reliance on paper-based systems which aren't easily shared across care settings. It is therefore the case that conversations around advance care planning may be initiated by different teams operating in different care settings, and each may have their own recording system which cannot be easily accessed by the

[7] University of Oxford Centre for Evidence-Based Medicine (2020). Advance care planning in the community in the context of COVID-19.
[8] Association for Palliative Medicine (2020). COVID-19 and palliative, end of life and bereavement care in secondary care: Role of the specialty and guidance to aid care.
[9] National Institute for Health and Care Excellence (2020). COVID-19 rapid guideline: Managing symptoms (including at the end of life) in the community. [NG163].

others. Some GPs may record advance care planning as part of a patient's Key Information Summary (KIS), but this presents separate challenges as not every patient has a KIS, the tool isn't universally used by HSC professionals and, even when a patient has a KIS, it cannot be updated by secondary care professionals – only the person's GP.

19. It is hoped that the Encompass IT system may have the capability for information on ACP discussions/decisions to be recorded and accessed by health and social care professionals across care settings, although we recognise that it will take some time before this system is ready. The patient portal for people with dementia, initially launched in 2018 to allow patients, carers and clinicians to share information, may provide another route to transcend existing ACP barriers.

20. Marie Curie would also point to the Coordinate My Care system, currently operating in London, as a best practice example of how the recording and sharing of advance care planning can be done more efficiently. Coordinate My Care uses an online portal to document advance care plans and make them accessible to a wide range of HSC providers, including care homes and ambulance staff. GPs make referrals on behalf of care home residents, after which a registered nurse works with the person, their loved ones and the care home staff by telephone to complete the advance care plan. In response to the COVID-19 pandemic this service was expanded to cover all Clinical Commissioning Group areas in London.

21. In the context of the issues highlighted above in relation to DNACPR, it is important to note that the Palliative Care in Partnership Programme (PCiP) [10] submitted an updated DNACPR policy to the Department of Health for consideration/approval in December 2017. A new workplan for the development of an overarching ACP policy, which will include DNACPR, is underway and is due for completion by May 2021

Recommendations:

- All care home residents should have a timely opportunity to discuss and record their future wishes and preferences for care, with HSC professionals adopting the approach to treatment and care planning that is recommended under NICE guideline NG163.
- Solutions should be explored to make the advance care planning process – including recording ACP conversations and sharing this information with relevant HSC professionals – quicker, easier and more efficient for care home residents.
- A public engagement exercise is required to promote the benefits of advance care planning for care home residents, dispel myths about the purpose of ACP and counter the negative narrative that has developed about DNACPR.

VISITING AND ISOLATION WITHIN CARE HOMES

22. Restrictions on visiting in care homes and other settings, while absolutely necessary to tackling the spread of COVID-19, have taken their toll on residents and their loved ones. Marie Curie nurses providing support to care homes have noted the impact, with people having to use digital technology to stay in contact and, at times, say goodbye to their loved ones before they die. Given the health status of many care home residents – in particular, the high prevalence of neurodegenerative conditions like dementia – even this technology will not provide a viable option for some. Overall, the situation has caused significant distress to some care home residents and their loved ones.

23. Marie Curie supports the government guidance on visiting as an important step to protect vulnerable patients and stop the spread of COVID-19. The scenario outlined above, however, reinforces even further the importance of:

    a) Palliative support for residents, to help address the emotional and mental impact of being unable to see their loved ones as often as they would like.

[10] The Palliative Care in Partnership Programme is responsible for enhancing palliative and end of life care services across Northern Ireland. It includes representatives from NI's five Health and Social Care Trusts, the Department of Health, HSCB and PHA, NIAS, hospice and independent palliative care providers, community and voluntary sector representatives, ICPs, primary care representatives and service users and carers.

b) Clear public messaging and information for loved ones on when visiting is permitted and why the restrictions are necessary.

c) Bereavement support for the loved ones of care home residents, to help address any complex grief reactions arising from lack of opportunities to visit and say proper goodbyes.

FURTHER COMMENTS

24. Marie Curie warmly welcomes this inquiry by the Health Committee and would be supportive of a similar examination of the impact of COVID-19 on the domiciliary care sector. This sector also plays a critical role in supporting people who are terminally ill and, it is our understanding, has faced many of the same challenges as care homes during the COVID-19 pandemic.

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