HEALTH AND SPORT COMMITTEE

WHAT SHOULD PRIMARY CARE LOOK LIKE FOR THE NEXT GENERATION?

SUBMISSION FROM MARIE CURIE

About Marie Curie

1. Marie Curie provides care and support for people living with a terminal illness and their families and carers. Last year we provided care for over 7,500 people living with a terminal illness, as well as their families and carers across Scotland.

2. Our vision is for a better life for people and their families living with a terminal illness. Our mission is to help people living with a terminal illness, their families and carers, make the most of the time they have together by delivering expert care, emotional support, research and guidance.

The Scottish Government’s Vision for primary care

“General practice and primary care at the heart of the healthcare system. People who need care will be more informed and empowered, will access the right professional at the right time and will remain at or near home wherever possible. Multidisciplinary teams will deliver care in communities and be involved in the strategic planning of our services.”

3. We agree with the Scottish Government’s vision for primary care. We also broadly agree with the priorities and themes that have arisen from the public panels and survey, undertaken by the health and sport committee. In particular, we want to see a focus on:

- Improving access and processes across primary and secondary healthcare, as well as across tertiary and social care services.
- Communication and information sharing across primary, secondary and tertiary healthcare and social care services.
- The role of digital technology and data sharing among health and social care professionals across all settings.
- Engagement with primary care staff around palliative care including support for the new Palliative Care Directed Enhanced Service issued by the Scottish Government in April 2019.

4. It is important to note that primary care and social care cannot and should not be separated. Primary and social care should be partners in supporting people to manage their conditions and remain independent in their own homes and communities, and to return there quickly following any acute admission.

5. One of the recommendations from the panels was that the NHS should take over responsibility for social care from the local authority. We do not agree that this would improve primary care. Primary care is one of the functions delegated to integration joint boards (IJBs) and as such the context for the reform of primary care sits within health and social care integration. Integration is the best way to bring primary, secondary and social care together and the focus needs to be on making sure integration works to meet the needs of individuals, carers and family members.
6. However, we do agree that more needs to be done to improve processes, communication and engagement to ensure the aims of integration are realised. In particular, we believe that the third sector needs to play a greater role in the support and development of strategic commissioning plans and the delivery of services. The third sector provide irreplaceable services for people and families, which can support the work of primary care (and other settings). Improving these factors, in relation to palliative care, will form the basis of this submission.

Marie Curie services and our primary interaction with primary care

7. Our two hospices in Scotland, in Edinburgh and Glasgow, offer inpatient and specialist outpatient care and a broad range of day therapies to meet the needs of individual patients with a range of terminal conditions. We also provide specialist support in the community through our community nurse specialists who support people living at home, in care homes, prisons, and the homeless. We also support, advise and educate GP’s and district nurses.

8. Our nursing service delivers care and support to people in 31 local authority areas in Scotland. We mainly provide our services in people’s own homes, but we also offer support in hospitals and residential care homes. Our planned nursing services offer overnight care (typically 10pm to 7am) and shorter periods of care during the day, seven days a week. Our fast track services help prevent unnecessary hospital admission and enable rapid discharge, allowing terminally ill patients to spend their final weeks at home.

9. Marie Curie’s hospices and nursing services are commissioned in partnership with local Integration Authorities. For these clinical services, we accept referrals from GPs, district nurses (DNs), community specialist palliative care nurses, community or hospital allied health professionals (AHPs) and Macmillan nurses.

10. In addition to these clinical services, we also take referrals for our Helper volunteers service, which offers companionship and practical support to terminally ill people, their families and carers. We also provide nationwide support through our information and support service including our national helpline. People can self-refer to these services, but we also welcome referrals to them from healthcare professionals.

11. Our nursing and hospice teams work closely with primary, secondary and social care to ensure that people are supported in the way that is meaningful to them and possible in the context of their care.

12. Last year Marie Curie launched the Daffodil Standards in partnership with the RCGP. The Daffodil Standards are a blend of quality statements, evidence-based tools, reflective learning exercises and quality improvement steps. The standards offer a structure to enable practices to be proactive organisations in which continuous learning and quality improvement steps are an integral part of caring for people affected by advanced serious Illness and end of life care.
Our vision for primary care

13. Primary care plays a crucial role in supporting people who are living with a terminal illness and needing palliative care support, as well as their carers. On average 1% of any GP’s list of patients will die every year, meaning that every GP practice will be dealing with terminally ill and palliative patients. On average a person in their last six months of life will spend 90% of that time in a community setting, including home or their care/nursing home. This means they will be dependent on primary care services to live as well as possible during that time.

14. We know that at present a significant number of people with palliative care needs die without getting that support. An indicator of whether or not someone has received palliative care is whether they have an anticipatory care plan. In Scotland the Key Information Summary (KIS) which is managed by GPs provides this information for those patients with long term and terminal illnesses. Last year 69% of patients who died with a terminal illness had a KIS on death, which means that a considerable number of people with a terminal condition are dying without these plans, which could mean they have not been identified as palliative or had the appropriate care plans in place. Only 40% of those who died of organ failure had a KIS in place.

15. The future of primary care will also be challenged by Scotland’s demographic challenges, particularly those in relation to an ageing population, and one where the disease burden is forecast to increase considerably. The number of people dying each year is forecast to increase from 57,883 to 65,756 by 2040 meaning even cautious estimates show that an extra 7,000 people a year will need some form of palliative care before they die. There will be a considerable increase in levels of comorbidity, frailty, dementia, cancer, as well as the need for multiple medicine and drug regimens to support that (polypharmacy). With the number of people over 80 expected to almost double to 477,000 by 2040. Much of the support of this population will need to be served by primary care services. It is not clear to Marie Curie that Government strategies and local delivery plans have begun to face up to this future and we believe that planning for the future needs to begin now if we are to deliver sustainable service models which support this population and achieve our ambitions of delivering person-centred healthcare free at the point of delivery.

16. We believe that primary care needs to be in a position to support all those with a terminal illness from the point of their diagnosis and throughout their illness to their death. This should include supporting people and their families through identification, advance care planning, pain and symptom control, as well as emotional and spiritual support at any time of day. Primary care services from GPs to pharmacists and allied health professionals must work closely with each other and those in other care settings to ensure that the patient and their family receive truly person-centred care that supports their wishes and enhances their quality of life.

17. We believe that to ensure primary care is delivered in a way that focuses on the health and public health priorities of local communities, including those with palliative care needs, there needs to be fundamental examination of how primary care fits in with the wider health and social care system.

18. The right model is needed to support people to get to see the right person at the right time, in the right place. That needs to be supported by an understanding on who, where and when that is. There is a fundamental need for clarity in the Scottish health and social care
system, between both professionals and the public. There needs to be effective co-
ordination and communication to allow that to happen.

**Scottish Government policy**

19. The Scottish Government set out a vision in its 2015-21 Strategic Framework for Action on Palliative and End of Life Care that everyone who needs palliative care should have access to it by 2021. They followed this up in 2016 by pledging to double palliative care support in community settings and committing to ensure that everyone who needs a Key Information Summary will get one.

20. At present, it is the view of Marie Curie, that despite seeing some progress the ambitions of Government policy have yet to be met and with less than 18 months until 2021 considerable work needs to be done before this can be achieved. Primary care will play a pivotal role in ensuring that these ambitions can be achieved.

**Understanding, outreach and education**

21. There is a lack of understanding of what primary care does, how it fits with secondary and tertiary care, how it fits with social care and how it fits with care and support provided by third and independent sectors. This lack of understanding makes processes hard to understand, it means that people are unsure where they need to go to access support and who they need to speak to. This can leave people in states of confusion and frustration, which can further impact on primary care as GPs spend time on activities they should not be doing, and on secondary care through unplanned and emergency admissions.

22. Preventative action should be focused on making processes, and the co-ordination and integration of care easier for individuals to navigate. We believe this could help ease pressures on primary and acute services, enable people to live with their conditions and self-manage to become self-reliant, and able to contact the right services when they require more or specialised support. This should become the most important public health priority and public campaign in Scotland.

**Supporting structures and care coordination**

23. However, public awareness alone will not work. Structures need to be developed that will support people navigate health and social care. This needs to include a centralised co-ordination of care that makes sense to individuals. People need a single point of contact, within a team, that can advocate for them and help them with all aspects of health and social care. This contact needs to be based in the community, but with first-rate links to the primary care team, the NHS, social care and charities delivering services in the local area.

24. Several different initiatives have been developed, under a number of different names, to do just that. These include expert patient programmes, patient advocates and community link workers.

25. In Scotland, there are a considerable number of people living longer with multiple, chronic and increasingly complex conditions, and our research suggests this number is set to grow significantly. This group of people will all need significant planning and care coordination to enable them to continue living at home and in their communities. Currently GPs or specialist care providers spend a lot of time and resource co-ordinating and care planning.
26. At Marie Curie, we provide specialist palliative care. This type of palliative care often supports patients who have a complex terminal illness, whether that is at the end of life, or earlier in someone’s illness. More general palliative and end-of-life care can be provided by any healthcare professional, who may then seek support from specialist palliative care when/if needed. However, often people are referred to our services when they do not require the intensive level of specialist care that we provide, particularly with our hospices. This can be down to a lack of time or resource for others to co-ordinate and join up the care needed. Specialist services are only meant to see a small number of the patients who require palliative care. Health and social care services need to make sure that all patients have access to the right care co-ordination. This is often work that can be done by others and could be potentially be co-ordinated by community link workers.

27. The Links Worker Programme detailed below was developed in areas of deprivation to mitigate the impact of the social determinants of health. However, the model could be adapted for use across all GP practices and clusters, to act as patient advocates to help people understand processes, plan for appointments and co-ordinate future care. We believe that every GP practice, or GP cluster going forward, should have a dedicated link worker. We believe that such Link Workers should have training, knowledge and experience of palliative care, as well as considerable knowledge of the palliative care services and support available in their communities. Link Workers could play a key role in supporting aspects of anticipatory/advance care planning.

28. This approach would ensure better cohesiveness and continuity between different health and care providers and align with realistic medicine and anticipatory care planning. These approaches ensure that people get the holistic and person-centred care and support that they would prefer and is meaningful to them.

Case study - The Links Worker Programme

The Links Worker Programme was a Scottish Government funded programme which aimed at researching how the primary care team can mitigate the impact of the social determinants of health. The programme was delivered as a partnership between the Health and Social Care Alliance (The ALLIANCE) and General Practitioners at the Deep End (The Deep End), and delivery partners include SAMH and the Royal College of General Practitioners (RCGP).

The programme recognised the pressure that GPs and primary care colleagues are under. The GPs felt that they were often unable to respond effectively because of a lack of time and with difficulties in accessing community-led services which they knew would benefit their patients. The programme introduces a different skill-set in to the practice team as well as support the existing staff to adopt the Links Approach.

The Community Links Practitioner:

- Work directly with the practice population, particularly with people who are experiencing complex circumstances. They support people to identify goals and enable them to achieve those goals through identifying and enabling access to local community assets.
- Work with the primary care team, both clinical staff and non-clinical staff in order to enable them to adopt the Links Approach (see below).
• Work with local community resources, supporting them to become more accessible to people accessing them via primary care.

The Links Approach

The Links Approach is a primary care team development approach which engages the entire team in developing the capacity to support people to live well in their community through enabling better access to information, knowledge, skills, relationships and resources. The links approach was piloted in the 2011 Deep End Links Project and has been developed by the recent Bridge Project and Improving Links Project.


29. When people are living with a terminal condition, their illnesses can be unpredictable. (see Figure below) This can mean that they are receiving specialist palliative care, more general palliative care, or no care at all at different points on those trajectories. There may be times when they unexpectedly need medical attention. This can be especially difficult if it happens at night or at the weekend, when healthcare professionals and primary care teams might not be available.

![Trajectories of decline at the end of life](image)

Adapted from Murray, S.A et al. BMJ 2008;336:958-959

30. In Scotland, there is not enough provision to care for people when they need crisis care, particularly for those who do not need to access specialist palliative care services. This can often mean that people are admitted to hospital. Even when someone has an ACP in place, and is able to remain at home, a person may need new pain medicine in the night
which would require an out of hours nurse/GP, but this may not be available quickly enough. If it was, there would be no need for a hospital admission, but without it these people are likely to be admitted to hospital. Paramedics may also be unable to leave patients at home or homely environments due to inadequate personal or social care. Similarly, hospitals may be unable to discharge patients from accident and emergency or ‘front door’ assessment units, who no longer need to be there, due to lack of support. Most often this is due to a lack of rapid access to social care, and particularly personal nursing care that is the reason discharge cannot happen.

31. Primary care needs to be more accessible to patients out of hours to reduce inappropriate demand on hospitals. Primary care providers must work closely with community nurses, social workers and other community staff to provide a rapid response to the needs of patients and to make the reality of care closer to home. An example of good practice in palliative care are the Marie Curie Fast-track Service and the Marie Curie Rapid Response Service.

32. These models could be adapted and co-ordinated as part of the link worker role in GP practices and clusters, to support people living in the community that need out-of-hours, crisis or emergency care. This does not need to be exclusively for people with a specialist palliative care need but adopted to provide care and support for elderly and frail people who are more at risk. This is particularly relevant in rural areas in Scotland where geography can compromise care in the community.

Case Study - The Marie Curie Fast-track Service

The Marie Curie Fast-track Service offers short day and evening visits at home to provide health and personal care to people living with a terminal illness in Glasgow and Lothian.

Fast-track discharge services help people living with a terminal illness spend their final weeks at home instead of hospital or a hospice. The service also takes referrals to prevent avoidable admissions of patients to hospital or hospice.

Marie Curie coordinates the service to help patients’ safe, timely discharge to their homes, and give a short package of care afterwards. Both services offer general nursing care with symptom control, personal care and emotional support.

They assess the patient’s care needs, make discharge arrangements and organise support for the time straight after discharge. A team of senior Marie Curie Health and Personal Care Assistants are also available to support patients for three to seven days.

Staffing and training

33. As mentioned earlier within this submission, at Marie Curie we mainly interact with primary care through GPs and district nurses and these are the most common route of referral to our services. However, this process relies upon these key individuals having an understanding and awareness of the range of services that organisations offer in local communities, and how to refer into those services. In the case of specialist palliative care, they also need the skills and experience to recognise deteriorating patients who are dying or approaching the end of life.
34. At Marie Curie, we have received inappropriate referrals from primary care for those who do not require specialist services, but we have also received appropriate referrals that are too late to enable us to fully support people as they would like. The picture can be further complicated by people who are self-managing long term conditions and are approaching the end of life. Their care may not be co-ordinated by district nursing teams, managed instead by social care services, which means that they can sometimes also miss out on care. A care co-ordination role, such as a link worker, with dedicated links to a named social care contact could relieve pressures on the primary care team and ensure everyone gets the support they need. Any such role would need appropriate training and support and have the capacity to refer to specialist services when required.

35. Further pressures also exist within the current district nursing structure. A number of recent initiatives have had a considerable impact on district nursing and may have contributed to reduced referral rates to our services. This includes the development of Advanced Nurse Practitioner (ANP) roles and district nursing clusters.

36. An Advanced Nurse Practitioner is a Registered Nurse who has done extra training and academic qualifications to be able to examine, assess, make diagnoses, treat, prescribe and make referrals for patients who present with undiagnosed/undifferentiated problems.

37. ANPs make an important contribution to the NHS in a range of different settings. They can take on aspects of the medical workload to relieve pressure on GP time, which is highly relevant in view of the growing shortage of GPs, and in doing so they can often enable a patient to get the care they require more quickly, without seeing a doctor. However, these roles largely recruited from district nurses, who are highly qualified nurses that have undertaken a specialist qualification in community health. This has led to fewer district nurses in the community. This can create a fragile system for organisations, such as Marie Curie, whose services depend on the structure of community nurses for referrals.

38. Recent changes to develop district nursing clusters, sitting separately to GPs has created further disruption to referral systems, destabilising community care. Separating district nurses from GPs has added an additional barrier to communication, in an area where healthy and stable relationships with community nurses are key. District nurses need to play a pivotal role in integrated community teams going forward and there should be no additional barriers to them accessing and referring to other services.

39. We support the Chief Nursing Officer’s paper 3 on *The district nursing role in integrated community nursing teams* as part of the Transforming Nursing, Midwifery and Health Professions’ (NMaHP) Roles programme and the focus on palliative and end-of-life care within community and district nursing roles going forward.

40. Further barriers in co-ordinating effective primary care structures lies with the recruitment and retention of staff. This is particularly relevant in rural areas, but is not exclusively so, with pressures around pay expectations, agenda for change and pensions contributions. Health and social care staff need to be trained in the principles of palliative care, supported and valued. Team-working should be promoted, alongside investment in skills for health and care staff, and greater clarity about the respective roles of specialists and generalists within the team will enable more effective coordinated working.

41. Marie Curie and the RCGP recently launched its Daffodil Standards. GP practices will work towards the mark, which is based a set of eight quality improvement statements
designed to support primary care teams in delivering care to patients living with an advanced, serious illness or at the end of their lives, and their loved ones. GP practices commit to making improvements in at least three of eight core aspects of care each year, with the aim of having reviewed all of them after three years.

The eight Daffodil Standards are
- Professional and competent staff
- Early identification of patients and carers
- Carer support - before and after death
- Seamless, planned, co-ordinated care
- Assessment of unique needs of the patient
- Quality care during the last days of life
- Care after death
- General practices being hubs within compassionate communities

42. We believe that all GP practices should be supported to participate in the Palliative Care Directed Enhanced Service launched in April 2019. This will help improve the number of terminally ill people identified for palliative care and an increase in the use of Key Information Summaries by GPs.

A connected system

43. A truly coordinated and connected system of primary care is needed to ensure that Scotland’s primary care system is sustainable for future generations.

44. Currently the lack of provisions for sharing data across health and social care providers in all settings is one of the greatest barriers to effective delivery of care and support. People often have to undertake multiple assessments and have the same conversations with multiple professionals. Professionals should be able to spend less time trying, and failing, to communicate with each other. IT systems should be in place to connect different parts of the care system, combining health with social care and taking into account both mental health and physical health.

45. Communication is one of the most important aspects of ensuring people receive the care and support they need. One of the biggest frustrations our staff experience is not being able to access or share information. This is partly due to differing IT systems used within primary and secondary care and within different providers. In Scotland a number of different electronic systems are used to record patient information across public, independent and third sectors and between primary and secondary care.

46. In palliative care there are a number of concerns around access and data sharing that can hinder or be a barrier to effective care provision. For example, patients’ care and treatment wishes may be recorded within an electronic Key Information Summary (KIS) which forms part of their anticipatory care plan. There is no consistent approach to ACP documentation and currently no ACP documentation can automatically connect to the KIS, which creates a further administrative burden on GPs, as they are the only professionals able to update the KIS. Another example is system compatibility issues surrounding the use of Do Not Attempt Resuscitation (DNACPR) orders in end of life care. Conflicting electronic systems, and how data is reorganised within these systems, can lead to healthcare professionals being unclear on patient wishes. This is inadequate to support and communicate the complexity of people’s care across different health and social care organisations. There needs to be
mechanisms to consistently share information in a timely and accessible way, with an effective IT infrastructure to support it.

47. It is not clear how current plans to upgrade IT systems will enable better data sharing.

48. In February 2019, NHS National Services Scotland announced that a new framework contract to supply IT software to General Practitioners (GPs) across NHSScotland was awarded to EMIS Health (Egton Medical Information Systems Limited), Microtest Ltd and Vision (InPractice Systems Ltd) and the contract overseen by the national GP IT Re-Provisioning Project Board. The new GP systems are intended to be more intuitive and user friendly, offering extensive and improved functionality. They are expected to provide significant benefits including improved online services for patients, better monitoring and reporting, and remote and mobile access for primary care teams.

49. At the same time NHS Education for Scotland are working on a National Digital Service (NDS) with the aim to improve the quality and delivery of health and social care across Scotland by building a National Digital Platform for clinical data. The aim of this platform is to create one system for health and social care data that is connected, safe and accessible. This Platform is meant to be the single source of truth to access patient knowledge – transforming patient experience across health and social care settings and allow professionals to communicate with each other. The first model to be tested on the National Digital Platform is the ReSPECT (Recommended Summary Care for Emergency Care and Treatment) process. The ability to robustly communicate and access person-centred emergency anticipatory care information across all health and social care settings would transform the emergency care experience of palliative care patients and their families. The success of this transformative work depends on community services being enabled to engage fully with the National Digital Platform. The impact of this early work will lay the groundwork for the communication of all aspects of Anticipatory Care Planning which is so essential for equitable access to person-centred end of life care.

50. We would like to see a clear plan from Scottish Government for these systems to become integrated and information shared across settings and professions.

51. Wider data collection around population, needs, services and outcomes needs to be improved and also better available to support all those working across primary care settings including those provided by the third sector. Access to data relating to local populations allows those third sector organisations working in partnership with the statutory sector to better design and deliver services suited to the needs of those populations. Ensuring the third sector can have access to data from sources such as the Scottish Primary Care Information Resource (SPIRE) should be an important priority for the future of primary care.

Workforce

52. A major concern for Primary care surrounds workforce, which must be addressed as a matter of priority. The SPICe Briefing, Primary Care in Scotland, published to support this inquiry highlights a number of worrying trends in workforce data, especially concerning the number of whole time equivalent GPs, and the ageing nature of the primary care workforce.

53. An inter-linking problem with primary care workforce issues are those in social care. The problems facing the social care workforce can have a major impact on primary care
services and the ability of them to work in an integrated way in the community. This is due to many in social care facing low pay, lack of investment in personal development and an emphasis on times and task-focused rather than person-centred needs focused care. In addition to devaluing poor pay social carers often have no travel costs reimbursed and ridiculous timed visits with financial penalties if they overstay their visit. High staff turnover makes embedding generalist palliative care skills almost impossible in social care and care home teams.

54. Marie Curie does face recruitment challenges to services, as a result of a shortage of nurses and healthcare assistants. This can impact on ability to meet the needs of patients and families, as well as our level of service in those areas where we are struggling to recruit.

55. The Scottish Government needs to prioritise workforce planning across all health and social care settings as an urgent priority. Workforce plans must look to the immediate, short, medium and long term needs of health and social care and the Government must be prepared to make the substantial investment needed to develop a sustainable workforce to serve the needs of its changing demographics.

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