

We need to talk about Palliative Care

Macmillan Cancer

1. Macmillan Cancer Support is pleased to respond to the Committee's enquiry. Twice as many people die of cancer in Scotland as the next most common cause of death. In 2013, 15,764 people died of cancer in Scotland – 29% of all deaths, compared to 13% from ischaemic (coronary) heart disease. The number diagnosed in Scotland is growing – up 18% between 2004 and 2013, to 42,169. It's estimated that more than 2 in 5 people in Scotland will develop cancer during their lifetime. 66% of men and 70% of women were alive one year after diagnosis and five year survival rates are up - 48% for men and 54% for women¹. As more people live longer with cancer, their need for palliative care will increase to enable them to live well with their disease.

A: Access to palliative care

What are the barriers to consistent access to palliative care and how can those barriers be overcome?

Barriers to consistent access to palliative care

Misperception that all cancer patients receive good palliative and end of life care already

2. Palliative and end of life care has traditionally been associated with cancer, and there is a growing misperception that people with cancer are now sufficiently well served in this area. However two studies in Scotland² found that between one quarter and one third of cancer patients had not been identified as having palliative care needs. All cancer patients should receive the right palliative and end of life care, so they can enjoy the best possible quality of life, and die well.

Palliative and end of life care needs identified too late (or not at all)

3. For cancer patients, the final phase of illness (from the point where curative treatment is no longer deemed appropriate, or is not chosen) can range from several years in some cases to days in others. People can live up to five years with cancer that is not curable³, and cancer patients may need palliative care at any time following diagnosis.
4. Late diagnosis is an issue. There are four stages of cancer growth, depending on how far it has spread. In 2012/13, 76% of cancer cases in Scotland were diagnosed at stage 2 or later – 26% (6,423) at stage 4 i.e. cancer has already spread extensively. Cancer patients who are not diagnosed until the later stages of their disease are more likely to have had unmet palliative care needs for some time.

¹ Figures relate to 2007-2011

² Harrison et al (2012) study of six Scottish GP practices and Zheng et al. (2013) study of nine practices.

³ Data taken from the National Cancer Survivorship Initiative

No consistently understood definition of 'palliative and end of life care'

5. There are two types of 'palliative care' - specialist and generalist care.
 - a. Specialist palliative care refers to care provided in hospices and specialist units, and specialist palliative care teams in hospital and in the community.
 - b. Generalist palliative care refers to times where a person's palliative care needs can be provided by those working in generalist roles, carers and families.
6. 'Palliative care' usually refers to the holistic physical, psychological, social and spiritual care of an individual, and 'end of life' care usually refers to the last year of life.

Need for balance between 'specialist' and 'generalist' support

7. There will always be cancer patients who need specialist palliative care which recognises their specific cancer needs. The nature of cancer and its treatment poses specialist palliative care challenges e.g.:
 - a. Advances in drugs and therapies mean more cancer patients are being treated. They often deal, not just with their cancer, but with life-altering side effects of their treatment.
 - b. Cancer patients dealing with several rounds of toxic treatment may be making regular trips for treatment when they are feeling ill and fatigued.
 - c. The term 'cancer' continues to cause a heavy burden of fear and anxiety for patients and those that matter to them. These issues need skilfully handled help patients cope.
 - d. 'Cancer' refers to over 200 diseases, each with its own pathway and therapies, and advances in treatment happen all the time. This requires a wide range of skills and knowledge to deal with every eventuality.
8. Specialist palliative care teams work with multidisciplinary teams and liaise with others e.g. site specific clinical nurse specialists (CNSs), oncologists to provide the right care for each cancer patient.
9. Macmillan Specialist Palliative Care Nurses have been providing specialist palliative care for cancer patients for 40 years in community and acute sectors. They also play an advisory role in supporting their generalist colleagues to provide palliative and end of life care to cancer patients.
10. Not every cancer patient needs specialist support at every stage of their journey. Palliative care for cancer patients is also provided by generalist staff, friends and family. However, general staff can lack confidence to deal with the palliative care needs of cancer patients, or believe mistakenly that every cancer patient should be referred to a specialist. This can make it harder for specialists to focus on the patients who really need their help. Generalist staff should

receive the training they need to empower them to support the palliative care needs of cancer patients.

Need for better out of hours care

11. Between 2007 and 2011, half of all cancer deaths in Scotland occurred outside hospital⁴. Cancer patients in the community need palliative and end of life care round the clock, to prevent unnecessary distress and hospital admissions.
 - a. A recent English study⁵ found half of all patients dying at home received no/partial pain control. This must improve.
 - b. Macmillan Community Palliative Teams provide 'just in case' boxes with anticipatory pain medication for cancer patients at home.
 - c. Identification of those with palliative care needs would ensure patients are added to their GP's palliative care register. This would prompt discussion with the wider team and could also the opportunity to initiate advance/anticipatory care planning discussions.
 - d. Many out of hours' services are provided by primary care teams (including community nurses and community pharmacists) and care staff from local authorities, and staff in care homes. Up-skilling these professionals to provide palliative and end of life care will improve out of hours experience for cancer patients.

Continuity of care through transition

12. Collaboration between health and social care staff in managing the transition between care settings can be patchy e.g. ensuring the right equipment and medications are in place. The opportunity for advance/anticipatory care planning discussions will ensure information regarding future wishes and priorities for care is documented and shared via consistent use of key information summaries across care settings. Macmillan has called for every cancer patient in Scotland to receive a holistic needs assessment (HNA), to identify concerns and plan their care accordingly. Our 'Improving the Cancer Journey' (ICJ) programme offers a HNA to all cancer patients in Glasgow when they are diagnosed. 30% of ICJ clients who received a HNA were at the palliative stage of their disease⁶.

Lack of good quality data in Scotland

13. There is no reliable data collected in Scotland on prevalence of patients with palliative care needs (either overall or by diagnosis) or specialist palliative care services. The National Survey of Bereaved People (VOICES) only covers England, and the last similar Scottish study was undertaken by Audit Scotland in 2008. Much of the data which exists is based on estimates rather than actual Scottish data e.g. the London School of Economics' recent estimate that

⁴ ISD Scotland, Place of death from cancer 2007 to 2011

⁵ National Survey of Bereaved People (VOICES) 2014 – this data is not collected in Scotland.

⁶ ICJ Board report for period 5 Feb 2014 to 25 July 2015

10,800 people in Scotland may have unmet palliative care needs is an extrapolation based on a study which estimated numbers for England⁷. Reliable data collected in Scotland is needed to measure the size of need in Scotland, and provide a baseline for evaluating whether measures introduced in Scotland are achieving the desired outcome.

Overcoming barriers

Training and education for generalist staff

14. Palliative and end of life care is delivered by a wide range of health and social care professionals, but many receive minimal training in palliative and end of life care, leaving them feeling ill equipped and lacking the confidence to cope. Improved training could:
 - a. identify palliative care needs early
 - b. make better use of information to improve transition between care settings
 - c. enable sensitive discussion regarding ACP
 - d. provide better out of hours care, avoid undue distress and emergency admissions
 - e. recognise when patients need specialist palliative care, and know what to do.

15. Palliative and end of life care training should be made available at scale and in accessible formats to a much wider range of health and social care professionals. Macmillan provides education and learning opportunities for Macmillan professionals and increasingly for non-Macmillan clinicians with an interest in palliative and end of life care.
 - a. A series of palliative and end of life care study days for professionals in Scotland.
 - b. The Foundations in Palliative Care resource for Care Homes is a training package developed by Macmillan to facilitate learning for care home staff.
 - c. Macmillan's Practice Nurse course enables participants to improve their knowledge, skills and confidence when caring for patients with a cancer diagnosis and their families, including their palliative care needs.

Sharing experience of models of care

16. Macmillan has long established experience in palliative and end of life care for cancer patients. Much of the knowledge and expertise in pain control has emerged from the management of those with advanced cancer. Cancer can cause a wide range of pain symptoms (e.g. bone, muscular, nerve) which require different analgesic regimes.

⁷ Equity in the Provision of Palliative Care in the UK: Review of Evidence, London School of Economics commissioned by Marie Curie, April 2015.

17. Macmillan professionals are often consulted on pain and symptom management for patients with non-malignant palliative care needs, because of the high levels of skill and knowledge they must maintain in this area in order to support cancer patients. Macmillan is well placed to share its experience and expertise in providing this care to cancer patients.

When palliative care provision is based on needs, how can access to palliative care provision be assured across different conditions, locations and prognoses?

How could it be ensured that access to palliative and end of life care is equitable and available in all areas and for all types of terminal illnesses?

Understanding the condition-specific nature of palliative and end of life care

18. There is a growing misperception that palliative and end of life care is a generic speciality which can be universally applied across all conditions. While the principles apply universally - everybody deserves the best quality of life and a good death as defined by them – how this is achieved may vary depending on their condition and how it affects them. We know cancer creates a unique set of challenges (see para 8), and helping someone achieve their priorities will usually involve overcoming these. It is important that equitable access to palliative care does not become shorthand for a generic approach to palliative care *regardless of condition*.

Advance care planning (ACP)

19. Good palliative and end of life care transcends care settings and is consistent both in and out of hours. At the heart is a clear understanding of the needs and preferences of each individual. Advance/ anticipatory care planning facilitates the gathering and recording of this information, which must be accessible to everyone who is involved in that individual's care. Awareness of ACP and its importance, and the confidence to put it into practice can ensure that an individual's wishes are known to the professional, who should take them into account.
20. Key to success is education in palliative and end of life care across all health and social care and the third sector, to raise awareness and uptake of ACP. Better integrated IT systems would facilitate flow of information between settings, and robust data sharing protocols would protect patient rights and empower staff.

Clarity of funding for palliative and end of life care

21. In 2014, the Cabinet Secretary said that nobody should be charged for palliative and end of life care in Scotland. Recent changes in funding complex clinical care have replaced Continuing Healthcare (CHC) in Scotland - only those patients resident in a NHS owned facility will have all costs met, regardless of whether they are at end of life or not. Palliative and end of life care will now be funded by Health and Social Care Partnerships, but it is not yet clear how this will work. No cancer patient in Scotland should be financially disadvantaged as a result of these changes. It should be made clear to patients

at the outset how their care package is funded, and if there will be any charges to them.

What are the benefits and potential drawbacks of having a named healthcare professional for each patient/family in receipt of palliative care?

Single point of contact

22. A single point of contact can help with advocacy, signposting and co-ordination of care, as well as providing consistency and building trust - vital to emotional wellbeing.
23. Where cancer patients have been referred to a specialist palliative care nurse because of their complex palliative and end of life care needs, this will be their main point of contact. However a patient's cancer journey may stretch over a number of years, and the right person to act in this role may change as needs change. It can (but may not need to) be a specialist palliative care nurse or a cancer CNS. The GP and primary care team play a role, and the district nurse may be the best choice towards end of life.
24. In Glasgow, Macmillan's 'Improving the Cancer Journey' (ICJ) programme assigns a link officer to each person diagnosed with cancer. The officer meets the patient, completes a holistic needs assessment (HNA) with them, and co-ordinates the care plan signposting on to other services as appropriate to meet individual need. On average, 50% of IJC participants felt less distressed when they are followed up after their first HNA visit.
25. The main drawbacks of a single point of contact are around resilience and accessibility e.g. in the face of sickness and absence, and out-of-hours cover.

B: Initial conversations about palliative and end of life care

When is the right time to begin discussing options for palliative and end of life care who should be party to that discussion, who should initiate it and where should it take place?

How do health and care organisations ensure that the discussions about palliative and end of life care are taking place at the right time?

26. Discussions about palliative care may start any time after the point of diagnosis, depending on each individual's circumstances. It's important that conversations take place before a crisis, so patients have time to think through their wishes in advance. Evidence shows that early referral to palliative care leads to better quality of life, reduced symptom burden, less exhaustive care and lower costs.⁸
27. Often, a cancer CNS will hold initial conversations with patients and those that matter to them after their diagnosis and this could include discussions about

⁸ Pivodic, L. Et al., "Home care by GPs for cancer patients in the last 3 months of life: An epidemiological study of quality and associated factors" Palliative Medicine 2015.

their palliative care needs if appropriate. A cancer CNS has the skills to manage difficult conversations and a better understanding of the likely disease trajectory and care needs their patient is likely to face. A CNS is also well placed to refer a cancer patient to a specialist palliative care nurse if this is appropriate.

Who should conversation be with and what should be asked?

What is the role of carers and families?

28. Any conversation with cancer patients about their palliative and end of life care needs should ideally be led by them, with support from professionals. Not all patients will want to talk about their future, so the professional may need to initiate the conversation sensitively, and help the individual open up – in their own time.
29. The discussion should look at what matter to them - and cover clinical, practical, spiritual and emotional wellbeing. Common priorities are symptom control and freedom from pain, but others things can matter e.g. saying goodbye to a pet, financial issues.
30. A holistic needs assessment and the ACP are key tools to prompt and guide these discussions, and particularly useful for generalist staff who are less accustomed to having these conversations. Macmillan would like to see wider uptake of ACPs.
31. Professionals should be guided by the patient on who should be party to these sensitive discussions. Often, patients will want to involve family members and carers, but there may be others who matter to them.

What training and support is provided to health and care staff on discussing palliative care with patients and families and are there any areas for improvement?

Are health and care professionals adequately supported to hold these conversations?

What works well in discussing palliative and end of life care and how is good practice communicated?

32. Generalist health and care staff often lack the capacity and confidence to engage in these challenging conversations with patients and families. They may mistakenly believe that only a CNS can speak to cancer patients about their care needs, and this can lead to delays or failure for conversations to happen at all. Over-reliance on the CNS may have contributed to the lack of palliative and end of life care training for generalist health and social care staff. Reluctance of patients and their loved ones to open these conversations can also contribute to the challenge.

“I have found that family don't want to talk to the person they are caring for about palliative care. Some but not all consultants are happy to do this with the patient and family.”

Person Affected By Cancer, Macmillan's Scottish Involvement Group

33. Macmillan professionals have access to training in engaging in difficult conversations, and provide advice to their generalist colleagues, but Macmillan would like to see all health and social care staff receive training on difficult conversations with cancer patients. Providing this support at scale will take time and requires a cross-sectoral commitment, Macmillan is already engaged in some innovative projects:
- a. Funding for an education programme in NHS Ayrshire and Arran to upskill general nurses from acute and community care settings in palliative and end of life care. This was extended to include social care staff. A total of 88 participants completed the programme.
 - b. The Macmillan Primary Care Palliative Care Team based at Clutha House (NHS Greater Glasgow and Clyde) plan and deliver training to community teams.
34. It is also important that the emotional wellbeing of staff engaging in these conversations is protected. Health and social care staff can find themselves dealing with very challenging circumstances.

What are the challenges in recording and documenting palliative care priorities and how well are those priorities communicated between different health and care providers?

35. Promoting advance/anticipatory care planning discussions will ensure that palliative care priorities and the person's wishes can be recorded in an Anticipatory Care Plan and shared appropriately. Key Information Summaries (KIS) helps sharing key information with those involved in providing unscheduled care.
36. There's a need for more people to have input into the KIS and for the quality of content to be improved. Staff across care settings must be trained to safely initiate sensitive conversations around future care and make use of the ACP and its contents to ensure the patient's priorities are respected. It is also important to review and refresh the ACP regularly with the patient as needs and wishes can change, sometimes rapidly, especially towards the end of life.

What is the role of anticipatory care plans in supporting palliative care discussions and how can their uptake be improved?

How should information about palliative care be made available to patients and their family during initial discussions and how easily available is this information?

37. As discussed above, advance/anticipatory care planning discussions are critical in identifying what is important to patients (and their families where appropriate) regarding their future care. The outcome of these discussions should then be recorded and shared with the person's consent but should be supported by training for staff in their use.

38. It is vital that patients can access information which is specific to their condition which will help them cope with their palliative and end of life care needs.
- a. Macmillan has information centres in Scottish hospitals e.g. at the Western General Hospital in Edinburgh, and the Beatson West of Scotland Cancer Centre in Glasgow. There are also information resources in libraries across Scotland e.g. in Glasgow, Dumfries and Galloway, the Scottish Borders and Renfrewshire. Cancer patients and their families can go to obtain information and advice about all aspects of cancer including palliative and end of life care.
 - b. Macmillan has published a range of information including 'Your Life and Your Choices: Plan Ahead (Scotland)' providing a range of emotional and practical guidance for people facing a life limiting-illness and those that matter to them.
 - c. The Macmillan Support Line (MSL), manned by Macmillan nursing and welfare benefits staff, provides confidential expert help to any person affected by cancer. In 2014, the MSL received 291 calls in Scotland where the main topic was death and dying, or pain and symptom management. A further 608 calls were made to discuss psychological issues.
 - d. Macmillan provides a wealth of online information on different cancer types and treatments emotional and practical support, to help inform and empower people to manage their cancer, live independently and die well.
 - e. Macmillan Welfare Benefits Advisors help people affected by cancer, including enabling them to access the financial support they are entitled to when they are approaching the end of their life.

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