

## We need to talk about Palliative Care

### Pancreatic Cancer UK

1. Pancreatic Cancer UK welcomes the opportunity to respond to the Health and Sport Committee's inquiry on palliative care.

#### About Pancreatic Cancer UK

2. Pancreatic Cancer UK is the only national charity fighting pancreatic cancer on all fronts: patient and carer support; information; campaigning; and research. We provide a UK-wide, expert and personalised support and information service, staffed by pancreatic cancer specialist nurses. This provides easy access to the best and most up-to-date information on pancreatic cancer to patients, their carers and families. We also run online discussion forums for pancreatic cancer patients, their families and carers to enable them to share experiences, information, inspiration and hope.
  - 2.1 We fund innovative research that makes the most impact with limited resources and leverages additional investment - and development of new talent - through our own research expenditure.
  - 2.2 Working closely with patients and their families and carers, clinicians and other healthcare professionals, researchers, politicians and policy makers; we seek to increase awareness of the disease and campaign to bring about improved outcomes in care and treatment.

#### What has been your experience in terms of access to palliative and end of life care?

3. Access to good quality palliative care is vital for pancreatic cancer patients, both in managing the pain and symptoms related to the disease and the side effects of the treatment they are receiving. The 2011 Pancreatic Cancer UK report [A Study for Survival](#) highlighted some positive experiences, but also many stories of disjointed care and inadequate treatment relating to the management of pain and other serious side effects.
  - 3.1 Currently, we hear from patients and families that access to palliative care services across Scotland is mixed. There are variations in access to end of life care between different areas of the country, GP practices and even GPs in the same practice.
  - 3.2 Disparities in access to palliative care services also stem from a lack of awareness among patients of the services available to them. We often hear of older people in Scotland struggling at home, as they have not been made aware of palliative care services and are reliant on family members or neighbours to intervene.
  - 3.3 There is anecdotal evidence of patients experiencing long waiting times, of around three to four weeks, before having first contact with a

palliative care service. Follow-up care can also be variable due to poor staffing. For example, patients frequently go without palliative care whilst their Macmillan or hospice nurse is on leave as no nurse is available to cover the post.

- 3.4 Variations also occur between the type and level of care available for each person. This can be due to whether there is a hospice in a patient's local area, whether the patient has access to a team of community nurses (Macmillan, hospice or palliative) and whether the clinician is aware of how to refer the patient to such services. Pancreatic cancer patients often have complex palliative care needs, including support dealing with pain management, weight loss, nutritional issues and depression. It is essential that all local provision is able to accommodate each individual's needs.
- 3.5 In addition, some palliative services will only provide care to those diagnosed with a terminal cancer, whilst others will provide care to anyone with a chronic, long-term or life-limiting illness. This creates further inequalities in provision.
- 3.6 A key problem when it comes to accessing palliative care is that too often it is associated only with end of life care, when it should also be used for symptom management and to address the side-effects of treatment. Consequently, many people who are eligible for palliative care do not receive it, or only receive it in the last few weeks of their life.

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?

4. To ensure access to palliative and end of life care is equitable, all GPs and NHS trusts should have access to community palliative services, either electronically or in paper form. This should include information on what services are available in their area and the ability to refer patients to them.
- 4.1 We would like to see clinicians in primary and secondary care given regular communication from palliative services on how to refer patients to their services, the inclusion and exclusion criteria, and an explanation of the services provided.
- 4.2 GPs should also be immediately informed when a pancreatic cancer patient is discharged from hospital to ensure their ongoing palliative care needs are met.
- 4.3 The need for palliative care should be flagged up on the records of all patients with a cancer diagnosis, serving as a reminder to healthcare professionals. This could be built into the IT systems or checklists health professionals use at key points in the pathway. However, due to differing IT systems between trusts and GP practices, this may not always be possible. The Electronic Palliative Care Summary (ePCS) and the Electronic Key Improvement Summary (eKIS), implemented in

Scotland as part of the Gold Standards Framework, provide useful tools for flagging up patients' palliative care needs.

- 4.4 As well as improving communication between palliative services and GPs, we would like to see better information given to patients about the services available to them. 20 per cent of nurses who responded to a 2011 Pancreatic Cancer UK survey highlighted the need for better signposting and information for patients. Particular concern was raised about signposting and information related to palliative care services and other services that patients come into contact with following discharge from hospital or transfer to another treatment centre.
- 4.5 Ideally, palliative care services should be available to all patients with a chronic, life-limiting illness.
- 4.6 In addition, improving awareness of palliative care as appropriate for symptom management would help address inequalities in access by ensuring more patients eligible for palliative care receive it. This is essential for pancreatic cancer patients who may not always have a long time between diagnosis and end of life, but can improve during this period with symptom management.

Can you identify any areas in terms of access to palliative and end of life care that should be focused on as priorities?

5. To address persisting inequalities in access to palliative care, it is essential to ensure all GPs and NHS trusts have access to palliative services. This might require more funding to increase the provision of palliative care services in some areas or better strategic planning to improve the use of available services.
- 5.1 Improving communication between GPs and palliative services should also be treated as a priority. Not only would this make sure GPs are aware of palliative services available to their patients, it should result in better coordinated care and help to ensure patients' ongoing needs are met.
- 5.2 Specialist nurses involved in the care of patients with a terminal illness have the greatest opportunity to raise awareness of a patient's referral to palliative care services. The requirement to ensure all healthcare professionals involved in a patient's care are aware of their referral to palliative services should be included as part of the "tick box" agenda in the holistic needs assessment of patients. Ensuring that all patients in Scotland receive a holistic needs assessment, which can help identify when a patient should have access to palliative care services, should also be a priority.
- 5.3 It is of concern that frequently patients do not access palliative care services simply because they are unaware of them. To address this problem, better signposting and information for patients should be a priority.

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

6. Discussions regarding palliative care can be difficult and it is vital that all conversations with patients are handled sympathetically and with the needs of the individual patient in mind. Patients should be given the opportunity for such discussions to be held in private with their family and/or carers present.
  - 6.1 Discussions about palliative care may be initiated by the patient. However, we are aware that this is a difficult topic for patients and carers to broach. Patients and carers who do raise the subject may do so independently of one another, for example through support services.
  - 6.2 Any clinician with the appropriate training and skills, whether a consultant, GP or specialist nurse, should be able to initiate conversations about palliative care. Again, anecdotal evidence suggests that many healthcare professionals are also reluctant to initiate such discussions.
  - 6.3 Although palliative care is often associated with end of life care, it is not necessary to wait until a person is reaching the end of their life to begin palliative care. With good communication and assessment, palliative care can be introduced early on in the illness. It can be provided in conjunction with other treatments, such as chemotherapy, radiotherapy and diagnostics.
  - 6.4 To encourage the earlier introduction of palliative care, it may be necessary to rebrand it as “supportive” or “ongoing” care to reflect that it should not be limited to the last few weeks of a person’s life. We would like to see key workers or Clinical Nurse Specialists ensure that discussions about supportive care are available to pancreatic patients and held early on in their care pathway.

What works well in discussing palliative and end of life care and how is good practise communicated? Where do the challenges remain?

7. Regular communication between the different healthcare professionals involved in a patient’s palliative and end of life care is important to ensuring that the care the patient receives is well coordinated and meets their individual needs.
  - 7.1 Palliative Multidisciplinary Team (MDT) meetings in both community and in-patient settings provide a good opportunity for communication and should take place regularly. We would like to see a focus on ensuring all MDTs have regular meetings, as anecdotal evidence suggests that there is currently great variation in the frequency and depth of palliative MDT meetings across different regions.

- 7.2 It is also important to ensure there is regular, clear and honest communication between practitioners, patients and their families at all stages of their disease. We believe better training and support for healthcare professionals is needed to address variations in the quality and frequency of communication between practitioners and patients. To help address this, healthcare professionals dealing with patients with a terminal, chronic or life-limiting diagnosis should undergo mandatory training in communication, such as the Breaking Bad News course.
- 7.3 Discussions regarding a patient's palliative care are best conducted by a healthcare professional that will have ongoing contact with the patient, preferably their key worker or Clinical Nurse Specialist. This will help ensure that the necessary support is implemented and meets both the patient's and carer's needs.
- 7.4 Where possible and appropriate, conversations regarding a patient's end of life care should ideally take place at home, so patients are not exposed to long waiting times and limited to 10 minute consultations.

What is the role of Anticipatory Care Plans (ACPs) in supporting palliative care discussions and how can their uptake be improved?

8. Anticipatory Care Plans, such as Do Not Attempt Resuscitation Orders and Lasting Powers of Attorney, can be beneficial to patients, their families or carers and practitioners if well documented and properly communicated. They help ensure the patient's needs and wishes are met, reassuring and empowering patients, whilst also providing practical support to healthcare professionals involved in a patient's palliative care.
- 8.1 Discussions about ACPs should be managed by a health professional well versed in the subject, such as a hospice, Macmillan or palliative care nurse so that they are handled in the best manner and most appropriate way.
- 8.2 Sensitively asked questions from key workers to the patient and family about their knowledge of palliative care and whether they wish to access it once treatment moves from curative to palliative can help the process of introducing a patient to palliative care. Such discussions should be held regularly at meetings and appointments with practitioners and clinicians, at the speed and level of the patient's choosing. They should also be well documented so that any outcomes are properly recorded and implemented.
- 8.3 ePCS and eKIS may help improve the implementation and take-up of ACPs by storing information on them in one place, which is easily identifiable and accessible for any practitioner involved in the patient's journey. Monitoring is needed to evaluate the effectiveness of electronic information sharing systems and identify areas for improvement.

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

9. Patients should be provided with information explaining what palliative care is, how it is best managed and what services are available to them. This should include signposting to local palliative care services, such as hospices, charities and community nurses.
- 9.1 It is important that this information is communicated at a level and in a format appropriate for the individual patient. As well, as having information explained to them in a face-to-face discussion, patients should be given written information that they can keep and refer to at a later date.
- 9.2 Patients and carers should also be given information about how they can access 24/7 palliative specialist advice.

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?

10. The level of training and support practitioners receive varies from region to region. This may in part be due to disparities in the funding arrangements set in place by individual NHS boards and hospices and what training is available in the area.
- 10.1 Practitioners are not currently mandated to attend palliative or end of life care workshops, meaning the level of training they receive is in part dependent upon them wanting to access it.
- 10.2 Anecdotal evidence suggests that inconsistencies in training provision have resulted in stories of patients being told they have three to six months to live, but being given no information of local palliative care services.
- 10.3 All frontline healthcare professionals dealing with patients who have a cancer or terminal diagnosis should be required to undertake training in palliative care, such as the Breaking Bad News course and refresher courses. This should include training on how to give out information on palliative and end of life care.

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

11. There is no one-size-fits-all approach when it comes to determining when to initiate discussions regarding palliative or end of life care. The right time to hold these conversations will be dependent upon the individual patient and their circumstances.
- 11.1 Holistic needs assessments should be carried out at various key points during a patient's care pathway, including at the beginning and end of

primary treatment. Whether a patient should be referred for palliative or end of life care should be picked up as part of these assessments. As palliative care plays a crucial role in symptom management, holistic needs assessments carried out early on in the patient journey should also consider the introduction of palliative care.

- 11.2 There are tools available to help healthcare professionals determine when the best time to refer a patient to palliative care services is. For example, the Sheffield Profile for Assessment and Referral for Care (SPARC) is used as a screening measure to facilitate the referral of patients with advanced illnesses, regardless of diagnosis, to specialist palliative care. However, it is important that clinicians do not simply use these as a “tick-box” exercise and adequately explore and analyse the information collected.

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

12. There are various challenges associated with the recording and sharing of palliative care priorities.
- 12.1 In the absence of patient directives, the reliance is on the healthcare provider to document priorities appropriately and ensure that this documentation is available at a time when needed. This is a particular problem for out of hours (OOH) services.
13. Currently, there is a variance in the IT systems used by both NHS Trusts and GP practices meaning that healthcare notes may be documented on one or more systems that are not compatible with each other. This can create difficulties in the sharing of palliative care priorities, as not all practitioners will have access to the IT system necessary to access a patient’s palliative care priorities.
14. In Scotland, progress has been made on the sharing of patient care plans through the national rollout of ePCS and eKIS, which allow emergency services to access information on patient’s palliative care priorities during OOH. The focus should now be on monitoring the effectiveness of ePCS and eKIS, and ensuring that all practices in Scotland are using them.

## **Pancreatic Cancer UK**