

## **We need to talk about Palliative Care**

### **South Lanarkshire Council**

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

South Lanarkshire Council is committed to providing a person-centred response to all individuals requiring palliative care and there is a strong partnership approach within South Lanarkshire, working with health colleagues, the Third Sector and private agencies. The Council is a partner in the Palliative Care Strategy for Lanarkshire.

Practice does vary though and there are difficulties in supporting people's wishes, often to pass away at home. This can be because of the lack of available homecare for example. Rural areas can be particularly problematic when colleagues are wanting to offer a person-centred approach to someone requiring palliation. Palliative care is multi-faceted though and differs from end of life care of course. Palliative care may continue for months/years and so affords greater opportunity to plan and to support a person's wishes for a 'good death'; this piece of work is carried out sensitively in terms of the exchange model of assessment and in adhering to the values and principles underpinning self-directed support. Where a person's care needs are deemed 'stable and on-going' self-directed support will be offered and the accompanying funding choices. Carers are also offered self-directed support where eligible.

The Council strives to offer the best person-centred practice in terms of end of life care and good practice does dictate that a Case Discussion is held prior to someone being discharged home to pass away; to agree roles and responsibilities (and who the Lead Professional will be). In reality, this does not always happen and there is room to improve end of life care within South Lanarkshire.

The Council is actively promoting Anticipatory Care Planning with NHS colleagues in supporting people to plan for their health and care needs and the form of intervention that would best meet their needs.

2. 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 illnesses?

In part, this is about having available resources to bring about equity of provision. For example, the Council is a key partner in Lanarkshire's Cancer Strategy and actively involved in the 'Living with and Beyond Cancer Workstream', which seeks to improve people's experiences. Substantial funding has been committed to supporting people with cancer and their carers across Lanarkshire but in other areas of palliative care (eg: Dementia, COPD, Motor Neurone etc) arguably funding commitments are much less. Though funding is one factor, developing a palliative care pathway that is fully operational and adequately resourced is perhaps the most obvious way forward after scoping out the issues people face across Scotland.

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

The hospital discharge process has to work effectively for this client group and the needs of those requiring palliation should be prioritised. These needs may be in terms of social care provision, psychological/spiritual needs, pain management (eg: a holistic approach is needed). It would be beneficial for people to always have a Lead Professional allocated at the point of a hospital discharge or indeed if supported within the community. A person-centred approach should be offered where possible and if someone is eligible for self-directed support and chooses, for example a direct payment by way of a funding option, their 'case' should be prioritised to ensure they are not disadvantaged in terms of the duration this may take. Respite/short-breaks should be prioritised where possible for this client group and this may necessitate further research into the needs of people requiring palliative care and of carers' needs. People also need to be confident that weekend support is available when required; that palliative care services do not only operate Monday-Friday.

4. 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?

This should be offered to the person for him/her to decide the level of support they feel they should need, whether to involve their family, children etc in discussions. Again, this should be a person-centred approach but supported by an identified Lead Professional. This may take place within hospital, within the family home or perhaps within a hospice. There should not be a prescriptive model imposed on people at such a difficult time in their lives. Agencies such as The Haven and Maggie's that are present within South Lanarkshire have a vital role to play in terms of their approach, which is therapeutic and person-centred. Discussing palliative care/end of life care, though clinical in many respects must also be sensitively approached adhering to the social work values of respecting self-determination, treating the person as a whole, promoting human dignity and so on.

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

People often speak of the 'horrible moment' where Consultants have said, "I'll get the Nurse to come in". It is often at this time that individuals will say they knew what their diagnosis or indeed prognosis was before it was said. There is room to ameliorate how bad news is delivered, not only to individuals but to family members too. Carers often speak about feeling 'cast adrift', of the complexities of negotiating what can appear to be a difficult and complex health and social care system and of managing multiple medications. Within South Lanarkshire, there are a number of services to support people requiring palliative care and their families and where a holistic assessment works well and services are co-ordinated people can and do receive excellent care. However, standardising this remains a challenge. Challenges remain in terms of awareness raising (for professionals and patients/service-users); letting

people know what is possible and how to access good palliative care support. There are gaps in provision for counselling/psychological support for carers and often in follow-up support after someone has passed away.

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

Anticipatory Care Plans (ACPs) have a vital role in supporting people to plan for their health and care needs. Though not a legal document, the lead for the ACPs remains with health colleagues though greater awareness of them is increasing across health and social care. ACPs are promoted across South Lanarkshire though historically they have been viewed as tools to support older people only. This assumption does appear to be changing. Better advertising of ACPs is arguably needed (concerted efforts in the local media for example and within GP practices). The ACP should form part of a holistic needs assessment offered to people requiring palliation. Again, they must be sensitively discussed and people must be reassured of their data being stored securely but shared at the appropriate time across health and social care.

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

Discussions should always be handled sensitively and from a person-centred angle using the exchange model of assessment. Information should be made available at the right time and in the right place so that distress is not caused. People often speak about being given information at the point of diagnosis only to not take anything in. This could be improved. Arguably, as and when people start treatment the Lead Professional could provide information. However, it must be respected that some people want no information, some will want a little and some a lot. Again, a person's right to self-determine their final months/years should be respected.

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

Training varies though within South Lanarkshire Council, there is a clear commitment to staff training and development (eg: funded Counselling Skills courses for those practitioners interested in palliative care, dementia training at varying levels and so on). Using a counselling skills approach can be taught and arguably this is something that could be further explored across the fields of health and social care for those practitioners working within palliative care. Care home staff are also trained in supporting people requiring palliation and in offering support to family members.

9. How do health and social care staff ensure that the discussion about palliative care and end of life care are taking place at the right time?

This can be discussed through the PDP/PDR process (clinical supervision) but should also form part of the pathway addressing the needs of

patients/service-users and carers. It should form the part of any holistic needs assessment to ensure that people are informed and that their rights are upheld (this may mean advising people about Power of Attorney for example). People diagnosed with lung cancer for example may not want to be told about accessing a hospice at the point of diagnosis. Though the prognosis for this time of cancer is poor, this also evidences the need to set and adhere to a pathway for support (holistic and not just medical) and to set key pieces of information against this, almost as a journey of continuing palliative care support.

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

Priorities are communicated through a range of forums such as through the Palliative Care Managed Clinical Network, Lanarkshire Local Hospices Forum and so on. Health and Social Care Integration offers the opportunity to re-focus and to re-prioritise palliative care and end of life provision within South Lanarkshire and this inquiry perhaps come at the right time to ameliorate services and support.

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