

We need to talk about Palliative Care

Scottish Independent Advocacy Alliance

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

Evidence suggests that many people who need palliative care in Scotland are not accessing it; we know from our members that often people with dementia are not able to access palliative care. We are also concerned about how people with Learning Disabilities might be supported to access palliative. There needs to be clarity regarding definitions of palliative and end of life care as they are often used interchangeably but are different.

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 terminal illnesses?

We believe that it would be helpful to have general training about what palliative care is for a wide range of professionals. Also specialist palliative care professionals should be available in a wide range of settings in order to ensure that as many people as possible who need palliative care are able to access it.

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

Health and social care professionals need to be confident to raise the issue of death and dying with the people they support and treat. Comprehensive training about palliative and end of life care would help to address this issue. We know that effective communication is crucial in helping people make sound decisions about the care and treatment they receive.

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?

The right time to begin discussions will differ from one person to the next. Independent advocacy plays an important role in helping people to make sense of their situation, understand their options and think about potential consequences. If people who are facing palliative care and treatment or end of life care had access to an independent advocate who was not a family member or friend and not involved in their care and treatment but was able to discuss their situation, help identify personal preferences, wishes and desires.

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

We know that when people are involved in their care and treatment and have a clear understanding of the situation they are more likely to plan ahead. Therefore people with long term conditions need to be supported

appropriately to plan for the future, discuss with their significant others as well as the different professional involved in their support, care and treatment.

6. What is the role of anticipatory care plans in supporting Palliative Care discussions and how can their uptake be improved?

This can play a crucial role in helping to ensure that people who need palliative care get the right support, care and treatment. In order to ensure the greatest benefit from anticipatory care planning they need to involve unpaid carers and significant others. Also they need to be shared with all relevant or appropriate organisations and professionals.

7. 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?

This will depend on the person and their situation but it would be most beneficial for a person to get access to information etc. at an early stage so they and their family and friends can prepare for the future. Some people may benefit getting support from an independent advocate to think through the issues, find out about their rights and make choices.

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The Scottish Independent Advocacy Alliance (SIAA) is Scotland's national membership body for advocacy organisations. The SIAA promotes, supports and defends independent advocacy in Scotland. It aims to ensure that independent advocacy is available to any person who needs it in Scotland.