Strengthening non-cancer palliative care in Fife: building on the best.

A workshop approach

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Acknowledgements
Members of the Non Cancer Palliative Care Action Planning Subgroup, Tricia Boyle, speakers and participants at the two workshop events.

Summary
The Fife Palliative Care Group set up a sub group to develop an action plan in response to the recommendations in the "The Fife Non Cancer Needs Assessment" report. This work is part of the "Joined up thinking joined up care" (Scottish Partnership for Palliative Care 2006).

Two very well attended workshop sessions were held, on 24th October 2007 in Rothes Halls Glenrothes and 29th November 2007 at the Vine Church Dunfermline. Sessions were open to carers, patients, health professionals, social service professionals, nursing homes and voluntary agencies across Fife.

This poster summarises the approach we used which built on good practice already having place. Key points arising from the two events later formed a substantive part of Fife's proposal for the Living and Dying Well Action Plan.

Our workshop approach
Event Aims
1. Review recommendations of the Fife Needs Assessment in light of current services and initiatives
2. Increase/raise awareness of palliative care principles and approaches already embedded and how to do more of our best and encourage the promotion of holistic care as standard
3. Gain a shared view on key priorities on next steps.

Focus
Focus was on holistic aspects of good care, not only on terminal care, solely of specialist palliative care.

Who was involved?
There was a great interest in these workshops which saw people attending across both workshops from a wide variety of disciplines, including:
1. Health, Primary and Acute Care - AHPs, nursing and medical staff
2. Social care: home care, social workers
3. Voluntary organisations: Crossroads, Macmillan Cancer Support, HCNA and Stroke Scotland, Motor Neurone Disease, Huntington's Disease, Renal Services, Mental Health Services
4. Respite care provided by care homes, long term care services
5. Home care support for cancer patients
6. Palliative care and stroke patients
7. Palliative care and end of life care education in a number of settings
8. Communication tool for patients with Learning Disabilities
9. Information and education of non-cancer palliative care within their own work set and arrangements.

Story telling sessions were held on the following issues:
• Cancer patients' story
• Palliative Care/End of life care education and professional perspective
• Home care support for cancer patients
• Palliative care and stroke patients
• Palliative care and end of life care education and professional perspective
• Communication tool for patients with Learning Disabilities
• Palliative care in dementia
• Specialist palliative care approach for cancer patients

Participants then considered how they could build on the best within their own practice.
• What this means to us in my/our area of practice?
• What is good in my/our area of work (eg geographical or specialty)?
• What do I/we need to do more of?
• What needs to be in place to support the development of my/our best practice?
• Task: Developing an influence map to develop local practice.

These findings were then considered alongside recommendations from the Fife Needs Assessment.

Areas for improvement
The workshops – some spent too much time giving information leaving not enough time to explore specific issues. It could have been shared in a session to the whole group then split to smaller groups to debate issues.

Workshop 1: identifying areas of good practice
There were many areas of good practice identified which were common to the joint work across Fife and examples included:
• Provision of palliative care education
• Good multidisciplinary working across health and social care in some services
• Improved communication with patient centred care plans
• Respite care provided by care homes, long term care services
• Community hospitals were acknowledged as a good resource.
• Out of Hours services

Workshop 2: identifying gaps in service provision
Across Fife there appears to be a general agreement on perceived gaps in service provision for palliative care patients with non cancer related disease. Gaps in services for this client group include:

• Better understanding of palliative care
• Lack of resources which included staff, time and financial support to develop services
• Lack of central co-ordination of resources
• Poor communication and poor multidisciplinary working creating difficulties in accessing/providing services for patient
• Lack of information
• Need for better sharing of information
• Access to overnight care in the community to support patients and carers

Positive comments on story telling
"Enjoyed the day - story telling sessions were interesting – identified the need for palliative care in non-cancer patients.

"Workshops were exceptionally good on the whole – valuable insight from story telling.

"Story telling was great – learning from people at grass roots and especially having caring here was very good.

Workshop 3: identifying support to improve services
Many ideas were put forward to support service improvements which included:

• Improved joint working and joint funding between health and social care
• Development of innovative and flexible ways of working across all services
• Development of an information/resource folder/directory for patients, carers, health and care professionals
• Further training and education in palliative care including joint training programmes to improve awareness
• Non cancer palliative care clinical specialist practitioners or enhanced training for generalists
• More involvement of patients and carers in delivery of care.

Positive comments on workshops
"Interacting with other disciplines and finding out most people are experiencing the same problems.

"The next steps workshop made me think of what I was doing and what I still needed to do.

Areas that need more emphasis
"Relationships between carers/patients/ professionals"

"Dementia group discussion – large number of people with this diagnosis.

"Financial issues (hospital care/v community) who bears the cost?" Valuable that medical/social services together. I hope this is the beginning of more joined up thinking.

"Accessible community resources for patients in hospital prior to discharge so that the staff can give this information when accessed to each patient needs the feel.

Figure 1: Participant votes for top 3 broad recommendations of Needs Assessment

Areas that need more emphasis
• Involvement of patients and carers
• Palliative care approach in cardiology
• Development of an influence map to develop local practice?

What are the needs to be in place to support service improvements?
• Better understanding of palliative care
• Lack of resources which included staff, time and financial support to develop services

Prioritisation of the recommendations in the Fife Needs Assessment
Participants were asked to prioritise their top three broad recommendations from the "Non Cancer Palliative Care Needs Assessment" as shown in figure 1. There was strong emphasis on general palliative care, coordination and support as well as strengthening service gaps.

Detailed recommendations from the needs assessment were also prioritised on the day.

Comments on the day
Positive comments
"Awareness for non-cancer palliative care service users and awareness that changes in service need to be made and are needed to it." "The information mapping and story telling allowed insight into all types of palliative care and how to try and improve care.

"Different types of workshops helped to keep audience participation.

Acknowledging gaps
"Too many success stories - for every success story there are many unsuccessful stories.

"Feel day still didn't recognise/fully acknowledge the inequalities experienced in non-cancer palliative care services.

Common themes and next steps
The Common Themes from the workshops centred on:
• Education and Training
• Communication
• Information for patients, carers and professionals
• Resources which included staffing, time resources, financial resources
• Partnership working including joint working and joint funding systems
• Service redesign.

These themes were reflected from all the different areas represented across Fife covering statutory, primary and secondary care and voluntary agency care.

There were many positive comments about the approaches we used in the events, though some participant had expected more direct information. Others were frustrated by the gaps and perceived a need for more resources. Participants were strongly committed to want to develop and improve systems to meet the palliative care needs of people with non cancer related illnesses across the whole of Fife.

The findings of the workshop were used to develop a draft action plan in response to the Fife Needs Assessment. These draft proposals then became the backbone of Fife's Living and Dying Well Action Plan and will also inform the development of Fife's Palliative Care Strategy.

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