

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

A workshop approach

Authors

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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”* (McLaren 2006) whilst also taking into consideration recommendations from *“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 Rothies Halls Glenrothes and 28th 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 happening. Key points arising from the two events later formed a substantive part of Fife’s proposals 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 creation of holistic good 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, or solely of specialist palliative care.

Who was involved?

There was a great interest in these workshops with 160 people attending across both workshops from a wide variety of backgrounds including:

1. Health, Primary and Acute Care - AHPs, nursing and medical staff
2. Social care: home care, social services
3. Voluntary organisations including: Crossroads, Macmillan Cancer Support, Chest Heart and Stroke Scotland, Motor Neurone Disease, Huntington’s Disease, Renal Services, Maggie’s Centre
4. Pension service
5. Care Homes.

Building on the best

Our workshop approach aimed to build on examples of the best there is in Fife and amplify that, using **story telling** from both a patient/carer and professional perspective. Story telling was used to illustrate issues and draw out areas of good practice or areas for improvement in Fife and encourage participants to discuss ways to improve noncancer palliative care within their own work settings and arrangements.

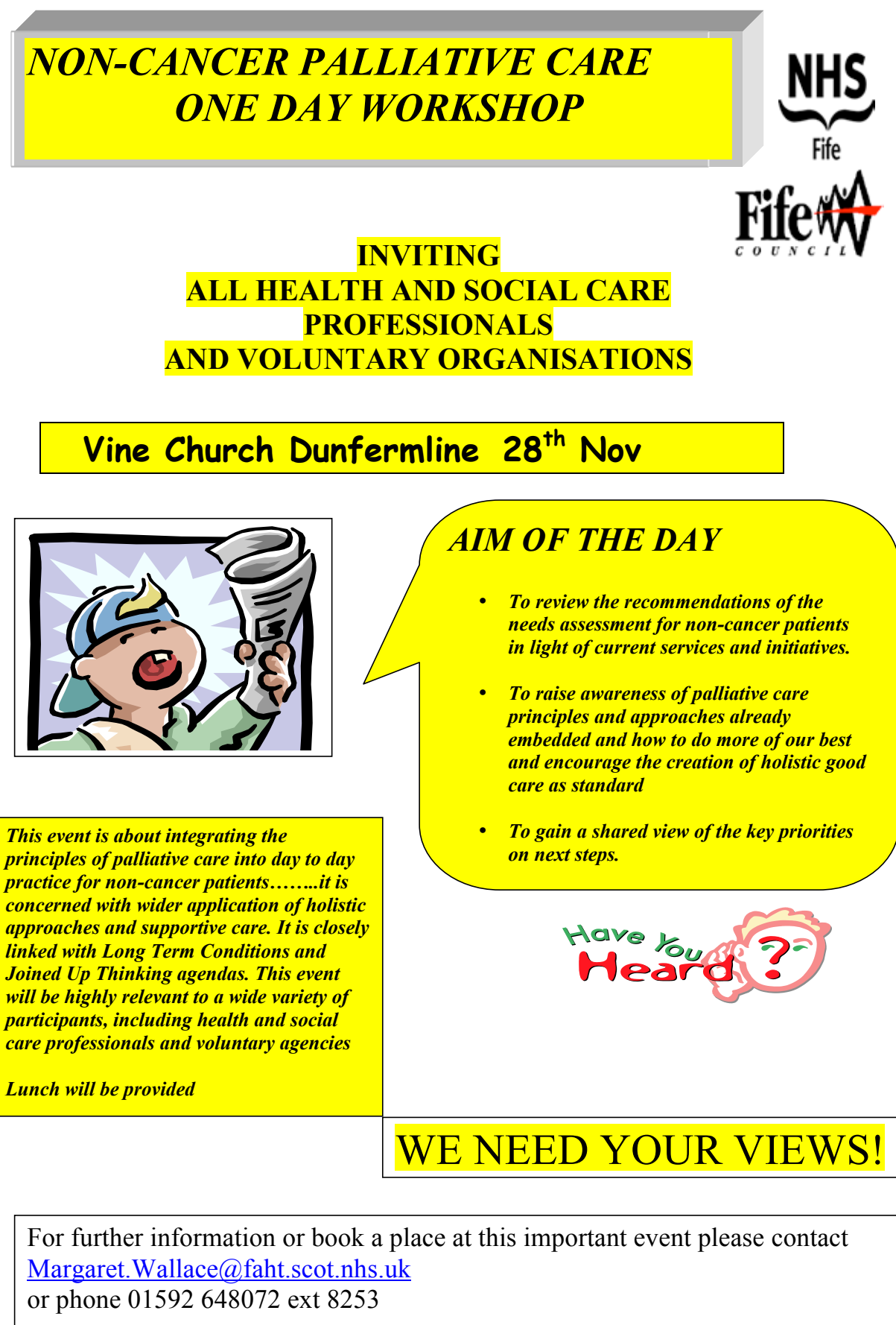
Story telling sessions were held on the following issues

- Cancer patient’s story
- Palliative Care/End of life care education in Care Homes
- Home care support for cancer patients
- Palliative care and stroke patients
- Palliative care approach in cardiology
- 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 me 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.



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 stories”

“Story telling was great – learning from people at grass roots and especially having carers here was very good”

Areas for improvement

“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 different areas 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 stay wards
- Community hospitals were acknowledged as a good resource.
- Out of Hours services

- Mental Health Services use palliative care approach
- Packages of care were good for those who did receive them
- Integrated response teams with easier access to services
- Support provided from carers support agencies i.e. Crossroads
- Specialist services support e.g. Parkinson’s disease Service, Inpatient palliative care unit for Stroke patients, Diabetic services patient support
- Access to 24 hour care for patients with dementia
- Primary care provided by GPs, District Nurses etc
- Disease specific support groups.
- Use of the single shared assessment
- Use of direct payment service.

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 included:

- Better understanding of palliative care
- Lack of resources which included staff, time and financial support to develop services
- Lack of a central co-ordination of resources
- Poor communication and poor multidisciplinary working created 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
- Difficulty in releasing staff to undertake education
- Understanding and ability to support self care
- Access to 24 hour crisis care
- Timescale for major adaptations to be undertaken in the home
- Insufficient access to psychosocial/ bereavement support for patients and families
- Lack of respite care for young adults and people under 65 years
- Responsive access to equipment services
- Waiting list system and time taken for care packages to be put together
- Need for more palliative care education at all levels
- Lack of day hospital and day care services
- Insufficient support for people over 65yrs with chronic conditions
- Possible over reliance on voluntary sector to provide services.

Workshop 3: identifying support to improve services

Many ideas were put forward to support service improvements which included:

- Improvement in 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 clinical specialist practitioners or enhanced training for generalists.
- More involvement of patients their families and carers in delivery of care.

- Improved financial support for carers.
- Professional support systems for staff.
- Increased resources which are realistic to demand.
- Develop needs led not service led services.
- Develop crisis care team which could provide up to 72 hours at home and print unnecessary hospital admissions.
- Extend non medical prescribing.
- Commitment to protected learning time across all disciplines.
- Further development of “Champions” in palliative care across disciplines.

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”

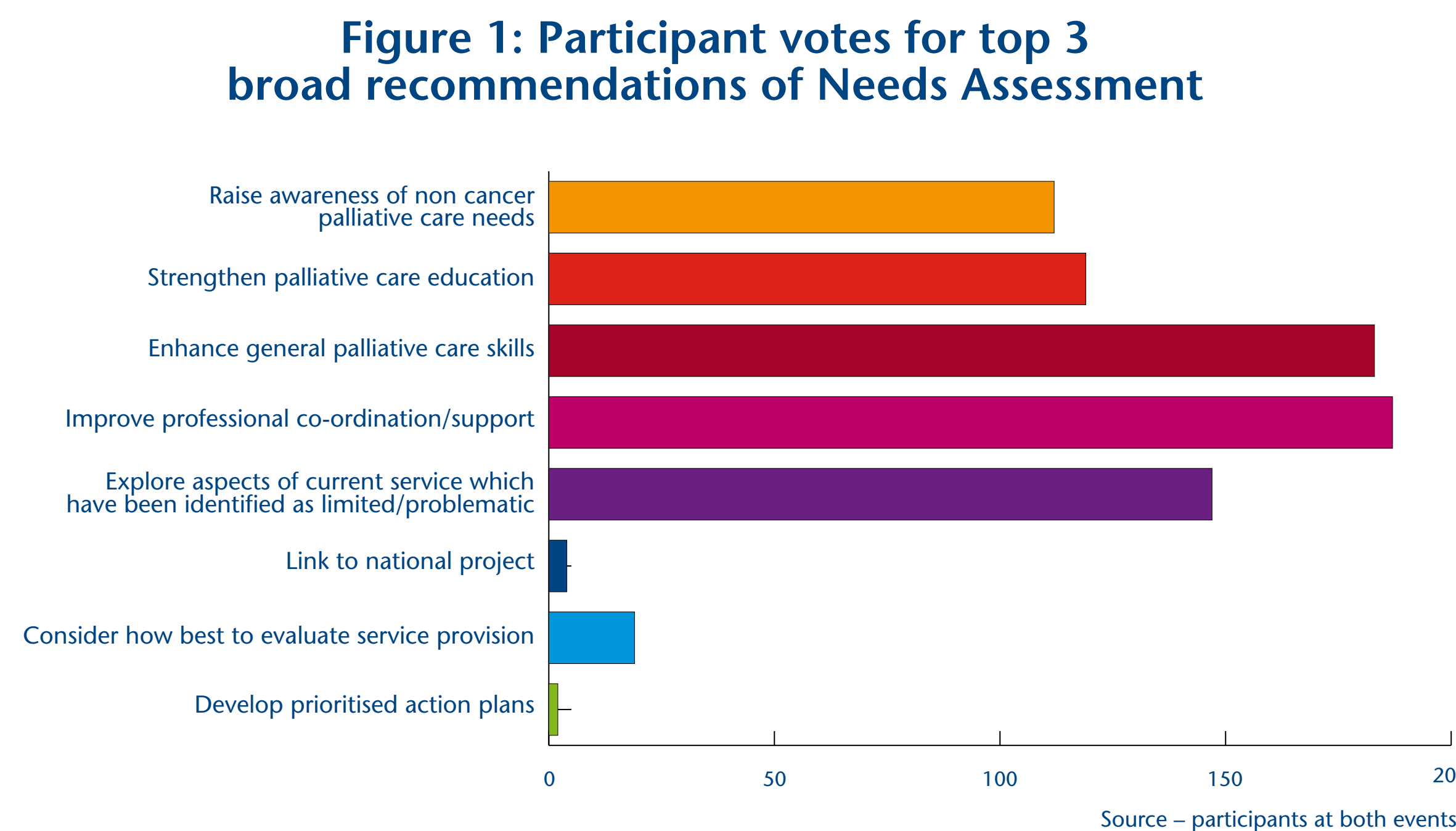
“Valuable that medical/social services together. I hope this is the beginning of more joined up thinking”

“Accessible community resources for patients in hospital prior to discharge so that the staff can give this information to be accessed when the patient feels the need.”

Prioritisation of the recommendations in the Fife Needs Assessment

Participants were asked to prioritise their top three broad recommendations from the “Fife 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 aspired to”

“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 resources, 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.

Contact

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