

Introduction

This report summarises the feedback from recent engagement on a consultation document, the Draft Strategic Plan for Palliative, End of Life and Bereavement Care. This document can be viewed at www.dghscp.co.uk/macmillan/palliative. The engagement was carried out by the Macmillan Cancer Pathways and Palliative Care Improvement Project Team (MIP). This feedback is being used to support the co-development of a Plan for Palliative Care for Dumfries and Galloway.

This was a piece of work to help identify what mattered to people in relation to palliative care. Further work will be undertaken to ensure that the themes identified through the analysis of this information, accurately reflects views across Dumfries and Galloway. This will support the co-development of action plans that will deliver future models of care and support.

Process

The National Standards for Community Engagement (2015) were used. We engaged with people who had accessed palliative care and support, Carers and staff who deliver palliative care and support. Opportunities to engage with us were available to all sectors of the Health and Social Care Partnership including statutory, independent and third sector organisations.

Methods

- Focus groups
- 'Drop by' sessions in the atrium at the Dumfries and Galloway Royal Infirmary (DGRI)
- Meetings and events
- Surveys - either on-line or in hard copy

Questions

People were asked

- What is working well?
- What is not working well?
- What might be changed or improved within current resources to improve services?
- What their views were on the 'Suggested high level ambitions' presented within the consultation document (see Appendix 1).
- If the definitions used within the document were clear and understandable

The engagement process was adapted to suit the individuals or groups at each session, responding to requests for different formats and presentation styles. 565 people engaged directly and the feedback received was open, honest and covered a wide range of experiences and views.

Demographics

The following information relates to the 49 people who answered the survey, as demographic data was collected through the survey, not at events.

Of those who answered, 26 (84%) identified as female and 5 (16%) identified as male, no-one identified as any other gender.

Ages ranged from 32 to 89 years old. The largest number of respondents was the 45 – 54 age range which consisted of 11 people (36%) (See Table 1, Appendix 2).

All postcode areas in Dumfries and Galloway (apart from DG4) were represented. DG1 had the most respondents with 9 people, equivalent to 18% of all those that answered.

Of those completing the survey;

- 23 people (48%) identified as a spouse, partner, other family member friend or unpaid Carer
- 10 people (21%) said they were employed in the statutory sector providing care and support
- 2 people (4%) work in the independent sector providing care and support
- 1 person (2%) said they were in receipt of care and support
- 1 person (2%) was a volunteer or member of staff in the voluntary sector providing care and support
- 11 people (23%) said more than one category of providing care and support applied to them

(See Table 2, Appendix 2)

- 46 people (over 95% of respondents) said they were interested in palliative care
- 42 (87%) were interested in end of life care
- 33 (68%) were interested in bereavement support
- Of those that put 'other', the majority indicated that more than one category applied to them.

(See Table 3, Appendix 2).

Feedback from surveys and focus groups

Definitions

When asked about the definitions of palliative care in the consultation document, 39 people (81% of survey respondents) felt they were clear and understandable.

This view was not shared by people who participated in focus groups. Focus group feedback indicated that the definitions were not clear or appropriate. A number of people, including staff and people accessing services, found them confusing and ambiguous.

We have listened to this feedback and will ensure that the definitions used in the Plan for Palliative Care are clear and unambiguous. Where possible we will also clarify how or, at what stage, people are identified as requiring palliative or end of life care and support.

Areas for improvement

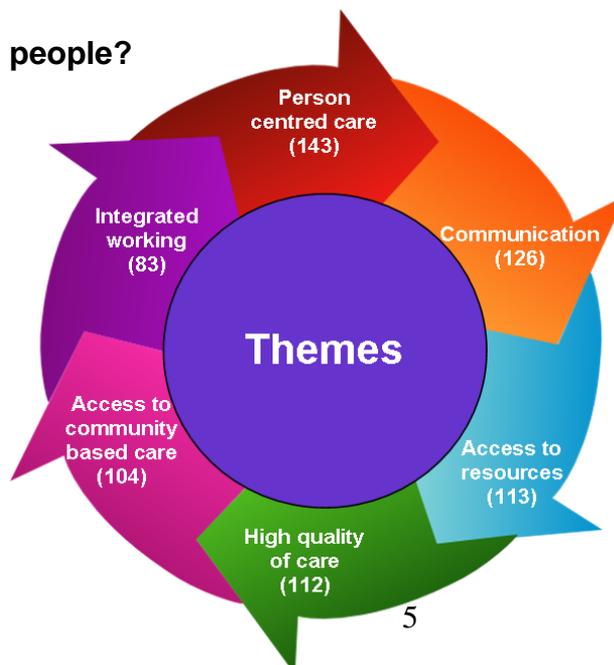
Areas that people felt were not working well or could be improved in relation to care and support are shown below in order of frequency.

- Access to resources (100)
- Person Centred Care (95)
- Communication (83)
- Access to community based care and support (63)
- Effectiveness and efficiency (61)
- Quality of care (58)

A summary of people's comments on these subjects included:

- Lack of understanding from people accessing and delivering palliative care and support regarding what the resource constraints are and improving effectiveness and efficiency.
- Greater level of investment in community based care needed, including within community hospitals and investment in staff training in all sectors
- Supporting people to have more control of their own health and well being and providing them with greater choice
- Improving communication and sharing information
 - Staff, families and Carers having a better understanding of what others do across all sectors and disciplines in order to signpost and access other relevant support
 - People having access to information about the care and support available
 - More integrated working and making paperwork, systems and protocols simpler
- Increasing wages for those in the Home Care and Support Sector
- Reducing health inequalities, increasing a person-centred approach and promoting quality of life
- Providing opportunities for staff (all sectors) and Carers to learn new skills and improve existing skills to support them to deliver high quality palliative care and support
- Improving resources (respite beds, number of staff, equipment)

Figure 2:
What matters to people?



The overall themes that came out of the comments across 'what is working well' and 'what is not working well', combined with 'suggestions for improvements' are outlined in Figure 2. This highlights what matters to people about palliative care and support.

Conclusions

People generously shared their views, providing us with access to a large amount of data which we will use to inform the development of the Plan for Palliative Care. The success of the Plan is dependent on the continued involvement of all stakeholders. This includes people who access care and support in Dumfries and Galloway, as well as those who are involved in its delivery.

Accurately reporting back the data and information that we have already gathered and using it to co-develop action plans will help to deliver future models of care and support. This approach will be used to meet the needs of everyone who accesses or delivers care and support in Dumfries and Galloway.

A Statement of Consultation is being created as part of the development of the Plan and will be available at the end of this process with the Plan for Palliative Care and associated documents.

Appendix 1

Suggested high level ambitions from consultation document

- Work together with people and communities, including those who use and those who deliver services within the resources we have.
- Improve our ability to identify people with palliative, end of life and bereavement needs. To plan care in anticipation, and in advance, of an individual persons needs
- Increase public awareness of, and community involvement in relation to death, dying and bereavement
- To allow people to spend more time in their preferred place of care, alleviate unnecessary suffering, minimise emergency admissions where avoidable, and support person centred choices
- Provide greater equity of provision that respects people's choices in their preferred place of death and creates sustainable services within the available resources
- Adopt the principles of "Best Value" in the services we provide and commission to achieve best experiences of care, best possible outcomes and best use of resources
- Progress in shifting the balance of palliative and end of life care towards greater community-based care
- Work together to promote a co-ordinated approach to bereavement care, both within the health and social care services and in partnership with relevant agencies and third sector partners
- Improve co-ordination of care, across all settings, to support people and their families who have palliative and end of life care and bereavement needs

Appendix 2

Table 1

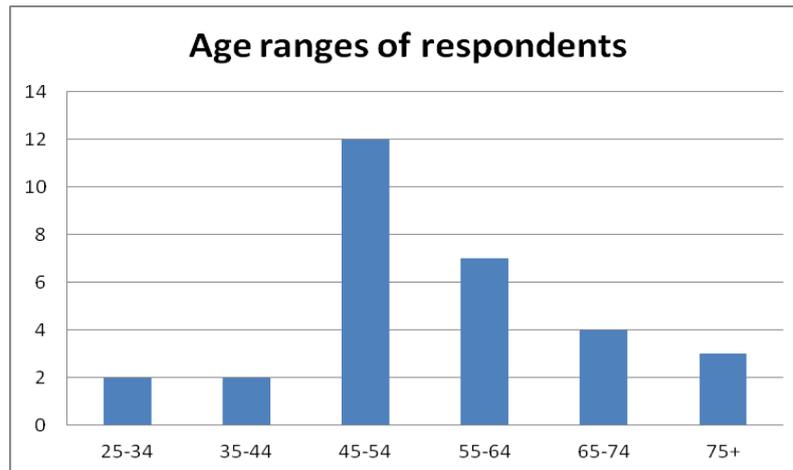


Table 2

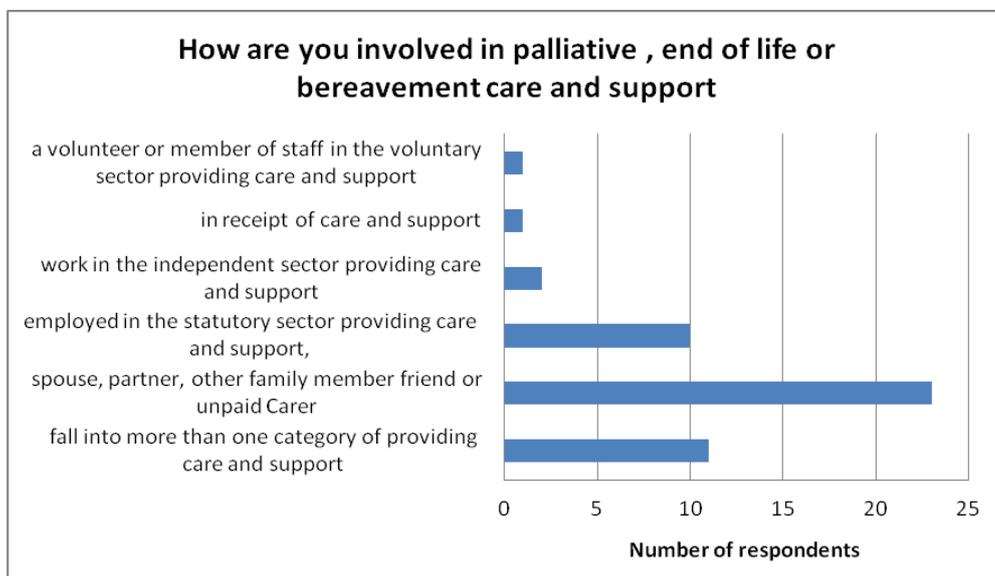
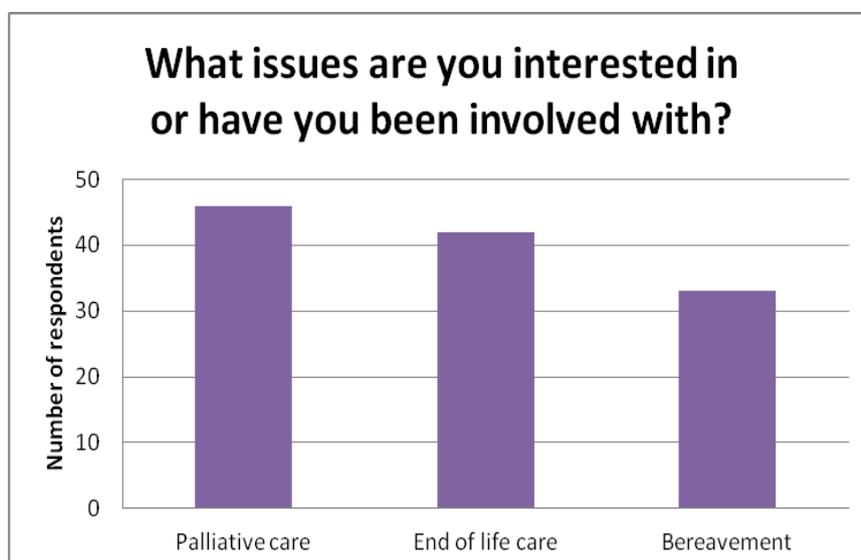


Table 3



Appendix 3

Comments about 'what is working well?' include;

- "Excellent compassionate care provided in the cottage hospital"
- "Marie Curie roving service is excellent, 9pm - 7am"
- "Team supports each other well and feel able to discuss with one another if affected by death"
- "GP was a great support and was really good at explaining what would happen at end of life and death"
- "DS1500 useful once in place"
- "Palliative Care Team support people in Midpark who are at the palliative phase of their illness"
- "Referrals come from multidisciplinary services"
- "Flow meetings work well"
- "Proactive not reactive care"
- "It was the small gestures of kindness and sensitivity that made such a difference to us"
- "The Alex Unit was fabulous in providing care to both of my parents"
- "Good working relationships within community services"
- "Staff committed and passionate about providing good quality care"

This report was prepared by the Macmillan Cancer Pathways and Palliative Care Improvement Project Team

If you would like to contact the team you can do so by telephone on 01387272725 or by email on dg.mip@nhs.net

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