



**Patient, Services User and Public Perspective
On
End of Life Care Strategy in Northern Ireland**

February 2010

CONTENTS

1 INTRODUCTION

2 BACKGROUND

3 THE PROCESS

4 REPONSES

5 KEY MESSAGES & RECOMMENDATIONS

APPENDICES

A COPY OF QUESTIONNAIRE COMPLETED WITH INDIVIDUALS

B COPY OF GROUP QUESTIONS

C STATISTICAL TABLE OF FINDINGS

D DETAILS OF PUBLIC EVENTS AND GROUP MEETINGS HELD

E BRIEFING DOCUMENT

F PRESS ARTICLE

1.0 INTRODUCTION

This report provides a summary of patient, service user, carer, and general public (the public) perspective on issues concerning end of life care in Northern Ireland. The information was collected by staff from the Patient and Client Council during a series of public events and ten focus groups. The report provides some valuable insights on a sensitive subject which should be of interest to policy makers, commissioners, and service providers. The Patient and Client Council would like to record its appreciation of the contribution and time given by members of the public and groups across Northern Ireland; without their valuable input this report would not have been possible.

The Patient and Client Council (PCC) provides a powerful independent voice for patients, service users, carers and communities on health and social care issues.

The statutory functions of the Patient and Client Council are to:

- Engage with the public to obtain their views on any part of health and social care;
- To promote the involvement of patients, clients, carers and the public in the design, planning, commissioning and delivery of health and social care;
- To provide assistance to people making a complaint relating to health and social care; and,
- Provide advice and information to the public about health and social care services.

The Patient and Client Council took the opportunity to comment on the consultation document, 'Draft Palliative and End of Life Strategy for Northern Ireland', issued by the Department of Health, Social Services and Public Safety (DHSSPS). In order that our response was informed by the views of the public, service users and representative groups the PCC held public and group events across Northern

Ireland throughout January and February 2010 gathering the views and experiences of the public on palliative and end of life care.

The purpose of this exercise was to ensure that the public had the opportunity to comment on and ultimately influence policy and how services are delivered.

2.0 BACKGROUND

The consultation document “Palliative and End of Life Care Strategy for Northern Ireland” was issued by the Department of Health, Social Services and Public Safety (DHSSPS) in December 2009.

The document details proposals for a five year strategy that provides a vision and direction for service planning and delivery for palliative and end of life care across all conditions and care settings. This vision emphasises the importance of the following five key areas:

- Understanding palliative and end of life care
- Best and appropriate care supported by responsive and competent staff
- Recognising and talking about what matters
- Timely information and choice
- Co-ordinated care, support and continuity

The consultation document sets out twenty-five recommendations that have emanated from the Strategy. These recommendations have been transferred into an Action Plan to enable planning and delivery of quality palliative and end of life care over the next five years.

3.0 THE PROCESS

Balancing the sensitivities of the subject matter with the opportunity for some true and meaningful engagement the process for carrying out this public consultation was carefully thought out. This was the first time that the public in Northern Ireland have been engaged in such an open and transparent way around the sensitive issues of palliative and end of life care.

In consultation with the DHSSPS, and using the 5 key areas:

- Understanding palliative and end of life care
- Best and appropriate care supported by responsive and competent staff
- Recognising and talking about what matters
- Timely information and choice
- Co-ordinated care, support and continuity

questions were developed to generate an informed response to the strategy. The PCC used the questions to engage with the public on a 1-1 and on a group basis. Questions were also available on the PCC's website. A copy of the questionnaire and group questions can be found at Appendix A and B respectively

All PCC staff involved in the consultation process attended bereavement awareness training to help equip them to approach members of the public with confidence when discussing such a sensitive issue.

Consultation took place in a wide range of venues including shopping centres libraries and health centres. This choice of venue offered the public an opportunity to get involved in a meaningful way in neutral venues.

In addition to the public engagement we consulted a total of ten groups representing palliative and end of life care. This ensured a comprehensive consultation process. These groups are outlined in Appendix C.

In total 181 questionnaires were completed. Whilst the majority of these were completed at public events, a small number of questionnaires were handed out for individuals to complete in their own time.

4.0 RESPONSES

The responses to the questions have been grouped under the 5 key areas

4.1 Understanding palliative and end of life care

The majority of people had some experience of supporting people with deteriorating health towards the end of their life (118 out of 181 respondents (65%)).

Some people reported receiving no support at all and others receiving support from a range of sources, including GPs, hospitals, hospices, charities such as Macmillan, Bryson House and Age Concern and other community groups. Many people praised nursing staff – Marie Curie in particular was seen as offering a fantastic service – but again it was noted that this was only available to cancer patients, and that people suffering from other conditions did not receive the same treatment and support. One lady spoke about her experience caring for her husband with Huntington’s disease, saying that there is only one specialist nurse in Northern Ireland for the condition. Another person spoke about the hard work necessary to get care structures in place but said that it worked very well once established. In some cases promises of support were not fulfilled, and most people, whatever their experience, felt that they needed more support than they received.

There were several suggestions on how to improve support for patients and their families and carers. Many felt that the help received at home could be improved if there were more regular assessments of patients’ needs in order to ensure that the most appropriate help was provided. Respite care was also an important issue for the people consulted – some reported having to fight for it and others were unable to receive any at all. Some highlighted the issue of continuity of staff, particularly for older patients who disliked having a constant stream of strangers in and out of their homes. They felt it was important for both the physical and emotional wellbeing of patients to be able to build a relationship with nurses, carers and home help. Other comments included the need for local chemists– one family having to travel 22 miles for prescriptions – and help with the costs of transport to and from hospital.

4.2 Best and appropriate care supported by responsive and competent staff

164 of respondents (91%) thought that there should be one person to coordinate patient care and advocate on their behalf. Opinion was divided as to who that person should be, with roughly equal numbers of people suggesting a GP, nurse or social worker. The majority didn't specify who the person should be, but all agreed that they should be accessible, flexible and knowledgeable and able to build a relationship with the patient and their family or carers. Respondents felt that a single person acting on the patient's behalf would eliminate confusion and '*crossed wires*', and help prevent the duplication and/or missing of information regarding the patient and their treatment.

There was a concern that healthcare professionals are already too busy and overworked, and that the role might be too much responsibility for one person to handle. Some said that the idea was a good one but may be difficult to implement in practice, and there was some cynicism that it might increase bureaucracy rather than cut down on it, creating jobs which detract from resources that should be spent directly on patients. Others commented that a range of people can offer the patient a mix of options, opinions and experience which can be beneficial.

4.3 Recognising and talking about what matters

The majority of respondents believed that there was a need for more open discussion about care. They felt that there was a stigma in society surrounding discussion about death and that an unwillingness to talk about it could magnify concerns, increase stress, and be isolating for the patient and their families or carers. Many people commented on the need for a general attitude shift in this regard, although it was also noted that discussions and the level of openness around end of life care should depend very much on the individual patient and what they can deal with, as for some people it might increase anxiety rather than minimising it.

4.4 Timely information and choice

83% of people asked would choose to stay at home provided they had good support from health and social care, primarily for reasons of comfort and familiarity, and the ease with which friends and family could visit. Everyone accepted, however, that depending on the nature and severity of the condition, some people need access to the 24 hour care that is only available in hospitals or nursing facilities. There was also widespread anxiety about the issue of burdening their families with their care, with some people saying that despite preferring their home environment, they would choose to go into a nursing home to “*allow their family to get on with their own lives*”. Many expressed worries about the necessity of having to sell their homes in order to fund nursing care.

Of the minority who said they would prefer not to be cared for at home, this was mainly due to the fact that they would feel safer in hospital and that they felt that adequate support could not be relied on. Everyone at the National Institute for the Disabled Group in Bangor (5 people) said they would prefer a care home. Again this was mainly due to worries about burdening their families, but they also mentioned the social benefits of the nursing home environment; a sense that it was less isolating, and that everyone was “*in the same boat*”. They also commented that it was often easier to have frank and open discussions about their care with nursing staff as it could be less emotionally fraught.

It was also noted that while experiences of hospital stays for the terminally ill were often negative ones for both patients and their carers, experiences of hospice care were generally very positive ones.

People felt that they needed both practical and emotional support. The overwhelming response was that patients, families and carers need to be kept informed at every stage of the illness so that they know what to expect and can make preparations. Information on practical issues such as writing a will, making funeral arrangements, advice on insurance, pensions, legal advice and other financial issues was seen as being very useful, along with helping the patient to consider issues such as organ donation; decisions relating to resuscitation and providing access to faith and counselling services.

4.5 Co-ordinated care, support and continuity

169 out of 181 respondents from public events (93%) responded that that a greater awareness of the availability of care is necessary, not just for patients but also for their families, carers and the general public. People are also unaware of the range of services and the ways in which they can go about accessing these services.

Patients and families talked about being “*afraid to ask*” healthcare professionals for information, and others reported difficulties in knowing precisely which questions to ask staff. Others felt that staff could be unwilling to help and that they felt they were “*wasting time*” by making appointments with their GPs in order to ask questions. Several people highlighted the need for more information to be made available regarding specific illnesses. There is a sense that there is a wealth of information about the help available for particular illnesses, notably cancer, but less for others.

Communication was one major issue highlighted by the consultation as one person spoke of “*literally having to drag information from doctors*”. Consistency of information was a problem too, with patients and families reporting having received conflicting information from doctors and other staff (in one case four different accounts of the patient’s condition from four separate staff); and in other cases there were problems with the duplication of information – patients having to give their histories several times for example.

One person speculated on a cultural tendency for people in Northern Ireland to “*keep things to themselves*” and to be wary of asking for help; others commented on feeling they had to fight for services they were entitled to. Information needs to be readily available therefore, and from a range of sources. One person made the point that many people still do not have access to the internet or are able to use it, and that phone numbers and postal as well as web addresses of information sources should be available.

The majority of people consulted spoke about the need for information to be available at as early a stage as possible to enable them to prepare, on both a practical and emotional level, for their own death or the death of a loved one. Having information early on in the process was seen as being important in facilitating care arrangements and managing expectations, thus reducing the potential for stress and anxiety on the part of both patients and carers. Many people were concerned too about the knowledge and availability of services for families and carers as well as patients, and the need for families and carers to be kept informed about the patients’ conditions.

Furthermore, the information that is available needs to be clear, accurate and free of medical jargon (simplified if necessary) in order to ensure that it is fully understood by patients and carers.

Good nursing and other care staff were mentioned by several people as being the most useful support that could be offered, along with someone who could be available to answer questions and give advice – the concept of a single key worker was raised again here.

Non-medical aspects of care and support were also important for many people, and cited as being often neglected. These included helping patients feel good about themselves by assisting with haircuts for example, and providing IT support to enable patients to communicate with friends and relatives who might be unable to visit. The issue of communication and combating the feeling of isolation was very important to many, and several people suggested a befriending scheme for those who live alone. Financial support and advice was also mentioned, and support for friends and families (such as better waiting room facilities in hospitals and follow up counselling following bereavement) were other key issues discussed.

KEY MESSAGES & RECOMMENDATIONS

The following recommendations evolve from the public responses to the specific questions posed:

- The majority of people consulted viewed better availability of information as a key priority. More accurate, timely and easily understood information plays a fundamental role to support people from which quality decisions can be made - 'If information isn't useful, it isn't information'.
- There is a real sense within the public's response to 'get rid of stigma and barriers' and to 'have a healthy discussion about death'. Such thoughts may prompt the Public Health Agency to consider an appropriate media campaign – something not referred to within the draft strategy.
- There was strong support for a 'key worker' for patients, clients and families, though there were varied responses as to who should fulfil this role (a GP, nurse or social worker were all recommended by respondents. Vital criteria for whoever fulfils this role include:
 1. Accessibility for the patient, their family and carers.
 2. Knowledgeable and able to answer questions.
 3. The ability to communicate well and establish a trusting relationship with the patient and their carers.
- The vital role of the carers was emphasised and the lack of respite and adequate care packages proved a common theme. Some people praised the work of voluntary organisations that provide support outside of the Health Social Care arena. It was also noted that provision of palliative care services is unequally distributed, with cancer patients in particular perceived as having the best quality and range of services. In part this is due to the work

of charitable organisations such as Macmillan and Marie Curie, but effort should be made to ensure equality of care for all patients.

- If more people are to remain in the community/their own home the need for properly resourced support services is critical. The primary concern for the vast majority of people questioned was the issue of burdening family members with their care. Better provision of care packages, home help and respite care will alleviate this concern.

The Patient and Client Council would concur that the strategy poses challenges and opportunities in developing palliative and end of life care over a 5 year period. The strategy in itself should assist in the drive for consistency of policy and care provision no matter where you live, however, a major challenge will be to ensure adequate resources allow for this strategy to be fully and effectively implemented.

Whilst the comprehensive action plan reads well in theory, doubt arises as to what can be practically achieved in an era of 'doing more with less'. Such concern was evident throughout our engagements – some questioned 'Where will the funding come from?'

None of the 25 recommendations within the strategy were disputed throughout the PCC engagements. It is important to note, however, that the questions asked were based on the recommendations of the consultation document. While this enabled the public to directly agree or disagree with the suggestions put forward there is also the sense that the decisions have already been made and views on these are simply being sought.



PALLIATIVE AND END OF LIFE CARE

The Department of Health, Social Services and Public Safety (DHSSPS) has asked the Patient and Client Council to comment on the consultation document 'Draft Palliative and End of Life Strategy for Northern Ireland'.

Palliative and end of life care refers to care of patients with an advanced progressive illness. It is an integral part of the care delivered by all health and social care professionals, and indeed by families and carers, to those living with, and dying from any advanced, progressive and incurable conditions

It is intended that this strategy will inform how palliative and end of life care should be developed, planned for and delivered across the public, independent, community and voluntary sectors. For the Patient and Client Council to provide an informed response we need to listen and learn about those who have views on this matter and indeed are able to share real life experiences.

We are therefore not seeking views on euthanasia or assisted suicide nor sudden death but rather, living and dying from any advanced, progressive and incurable condition.

Please print and complete this form and return it to us by the 15th February 2010, to the address on the bottom of the form. If you would like us to forward you a copy of the questionnaire, contact us at the telephone number listed on the bottom of the form.

Please circle or answer appropriately;

Gender: Male Female

Age Group: 0-30yrs 30-60y 60+y

Your nearest town (from home): _____

SECTION A

1a. Should people have more awareness of care for those who have an advanced, incurable illness and end of life care?

If yes, please give details:

If no, please give details:

2a. Have you any experience of supporting someone who has deteriorating health towards the end of their life? If no – please go to Section B

If yes, please give details:

3a. Did you get any support from health and social services (in hospital and/or community settings) or other bodies such as hospices or residential/nursing homes?

If yes, what worked well in terms of support? What could have been better?

If no, what support would have helped?

4a. Do you feel there should be one person (doctor, nurse, social worker) as a point of contact who would be responsible for co-ordinating patient care and, advocating on behalf of the patient during end of life care?

If yes, who do you think would be best placed to take on this role – anything in particular you think they should do?

5a. If no, with good support from health and social care would you prefer to be cared for at home?

Please return completed forms to the following address: Patient and Client Council,
Northern Area Office, Houston's Mill Site, 10A Buckna Road, Broughshane, BT42 4NJ
Tel: 028 2586 3950

Closing date 15 February 2010

Thank you for sharing your views with the Patient and Client Council

APPENDIX B - QUESTIONS FOR GROUPS

Palliative and End of Life Care Project

Group work - Questions

1. How well informed do you feel people are about availability of care for those with advanced incurable conditions and end of life care?

2. Do you feel there should be more open discussion about care for those with an advanced, incurable illness and end of life care?

3. What information do you think would be useful to help people plan for end of life care?

4. If you had good support from health and social care would you prefer to be cared for at home? If not, where?

- 4b. What type of support do you feel would be useful?

APPENDIX C - Schedule of Public Events and Group Meetings

Schedule of Events/Meetings – Palliative and End of Life Care Strategy

Public Events

Belfast Area Office	Northern Area Office	Southern Area Office	South Eastern Area Office	Western Area Office
27 January – Andersonstown Leisure Centre 9.20am-4.30pm	27 th January – Asda, Cookstown 10.00am-4.00pm	5 February – Buttercrane Shopping Centre, Newry 10.00am-4.00pm	30 January – Lagan Valley Leisureplex, Lisburn 10.00am-4.00pm	3 rd February – Quayside Shopping Centre, Derry 11.00am-4.00pm
10 February – Grove Health and Wellbeing Centre, Belfast 9.30am-4.30pm	28 January – Ahoghill Health Centre 9.15am-11.15am	8 February – Craigavon Area Hospital foyer 10.00am-12.00pm	1 February – Tesco, Newtownards 10.00am-4.00pm	4 th February – Strabane Library 11.00am-1.00pm
	5 th February- Asda, Coleraine 10.00am-4.00pm			

Group Meetings

Belfast Area Office	Northern Area Office	Southern Area Office	South Eastern Area Office	Western Area Office
28 January – Shankill Womens' Centre – crochet group 1.00pm-3.00pm	1 st February – The HIV Support Centre, Belfast, 7.00pm-8.30pm	28 January – Cancer Choices (cancer support group) 3.00pm-4.30pm	3 February – National Institute for the Disabled, Bangor 1.30pm-3.30pm	2 nd February – Derg Valley Healthy Living Centre 11.00am-1.00pm
	17 th February – Dementia Support Group, Ballymena 1.00pm-2.00pm	9 February – Local Womens' Group 8.00pm-9.30pm	4 February – Flying Horse Ward Community Group – Active Mind, Downpatrick 2.00pm-3.30pm	8 th February – University of the Third Age Fermanagh 11.00 am
				3 rd February – Friends of Termon Maguirc Carrickmore 8.00pm – 9.00pm

APPENDIX D - BRIEFING PAPER FOR GROUPS



Briefing Paper

Palliative and End of Life Project

January/February 2010

The Patient and Client Council would like to thank you for agreeing to meet with us. We welcome the opportunity to hear your views and experiences on palliative and end of life care in Northern Ireland. The information below is provided to help you understand the purpose of our meeting. Should you have any queries before or after we meet do not hesitate to contact **Paula Brown on 028 2586 3950**.

Who are the Patient and Client Council?

The Patient and Client Council is a brand new organisation, which has been set up to provide a powerful independent voice for patients, clients carers and communities on health and social care issues.

The main functions of the PCC are to:

- Engage with the public to obtain their views on any part of health and social care.
- To promote the involvement of patients, clients, carers and the public in the design, planning, commissioning and delivery of health and social care.
- To provide assistance to people making a complaint relating to health and social care.
- Provide advice and information to the public about health and social care services.

Why do we want to talk to you?

The Department of Health, Social Services and Public Safety (DHSSPS) has asked the Patient and Client Council to comment on the consultation document 'Draft Palliative and End of Life Strategy for Northern Ireland'.

Palliative and end of life care is the active, holistic care of patients with advanced progressive illness. It is an integral part of the care delivered by all health and social care professionals, and indeed by families and carers, to those living with, and dying from any advanced, progressive and incurable conditions

It is intended that this strategy will inform how palliative and end of life care should be developed, planned for and delivered across the public, independent, community and voluntary sectors. For the Patient and Client Council to provide an informed response we need to listen and learn about those who have views on this matter and indeed are able to

share real life experiences. We have designed questions that we would like your comments on; these will be discussed when we meet. The questions are available on our web site:

www.patientclientcouncil.hscni.net

Paper copies of the questions are also available for those who may wish to take 'time out' to share their views.

It should be noted that the Strategy has been developed and should be implemented within the existing legal framework. We are therefore not seeking views on euthanasia or assisted suicide nor sudden death but rather, living and dying from any advanced, progressive and incurable condition.

Background information on the DHSSPS Palliative and End of Life Strategy

The overall aim of the Department's strategy is to improve the quality of palliative and end of life care for adults in Northern Ireland irrespective of the nature of the condition they have, or where, or by whom, they are being cared for. The Strategy will provide a source of advice and guidance, primarily to health and social care commissioners and service providers, but also to patients and clients and those who are looking after them. This will ensure that people with palliative and end of life care needs, their families and carers are provided with high quality, consistent and integrated care, irrespective of care setting or condition.

The draft Strategy sets out a vision for palliative and end of life care across all conditions and care settings, based on what people value most and expect from such care. This vision emphasises the importance of:

- Understanding palliative and end of life care
- Best and appropriate care supported by responsive and competent staff
- Recognising and talking about what matters
- Timely information and choice
- Co-ordinated care, support and continuity

The consultation document and response questionnaire are both available on the Department's website:

http://www.dhsspsni.gov.uk/index/consultations/current_consultations.htm

APPENDIX E - STATISTICAL TABLE OF FINDINGS

Event	Total Responses	Should people have more awareness of care?			Have you experience of supporting someone towards the end of their life?			Do you think there should be one person as point of contact?			With good support from health and social care would you prefer to be cared for at home?			
		Yes	No	Don't know	Yes	No	Didn't respond	Yes	No	Don't know	Yes	No	Don't know	Didn't respond
27/01/10 Andersonstown Leisure Centre	13	13	0	0	10	3	0	8	5	0	9	0	4	0
27/01/10 Asda in Cookstown	25	25	0	0	16	9	0	25	0	0	24	1	0	0
28/01/10 Ahoghill Health Centre	15	14	1	0	8	7	0	13	1	2	12	1	2	0
30/01/10 Lagan Valley Leisureplex	8	8	0	0	4	4	0	8	0	0	6	1	1	0
01/02/10 Tesco Newtownards	14	13	1	0	7	7	0	11	3	0	10	3	1	0
03/02/10 Quayside Centre, Derry	23	23	0	0	15	8	0	23	0	0	13	0	10	0
04/02/10 Strabane Library	6	6	0	0	4	2	0	6	0	0	4	0	2	0
05/02/10 Asda in Coleraine	31	25	6	0	21	10	0	30	1	0	29	1	1	0
05/02/10 Buttercrane Centre, Newry	25	21	0	4	15	5	5	23	2	0	20	5	0	0
08/02/10 Craigavon	13	13	0	0	12	1	0	11	2	0	11	2	0	0

Hospital Foyer														
10/02/10 Grove Health Centre Belfast	8	8	0	0	6	2	0	7	6	2	5	2	0	1
TOTALS	181	169	8	4	118	58	5	164	13	4	143	16	21	1
% TOTALS	100	93%	5%	2%	65%	32%	3%	91%	7%	2%	79%	9%	11.5%	0.5%

Breakdown of responses to Question 4(a)

Do you feel there should be one person as a point of contact who would be responsible for coordinating patient care and advocating on behalf of the patient during end of life care? If yes, who do you think would be best placed to take on this role?

GP	Nurse	Social Worker	No specific person
22	15	12	32

18 January 2010

WHAT ARE YOUR VIEWS ON END OF LIFE CARE?

Do you have views on how people with a terminal illness should be cared for? Have you experiences within your family or friends that could help point the way to better end of life care? If so, why not visit the Patient and Client Council exhibition stand in the _____ on _____ to inform us of your views on palliative and end of life care?

The Patient and Client Council (PCC) is a new organisation that came into being at the beginning of April 2009. It was set up by the Government to provide a powerful independent voice in health and social care for patients, clients, carers and communities.

The PCC will do this by:

- involving you to help improve services
- asking you about your experience of health and social care
- listening to your concerns
- helping you to make a complaint
- achieving change together

/more

/2

The Department of Health, Social Services and Public Safety have asked us to respond to a draft Palliative and End of Life Care Strategy.

We want our response to be based on the public's actual experiences and views so we would like to hear from you. We have 3-4 questions that we would like your comments on. All information will be confidential but it will help us ensure that the views we express are based on real life experiences.

Jackie McNeill, Area Manager for the Northern Office comments
“ We plan to take our exhibition stand to a number of locations throughout the Northern area to seek views on palliative and end of life issues.

I encourage you to take a break from shopping to visit the exhibition stand, pick up an information leaflet and speak to the PCC staff member.”
The stand will be in operation from 10am – 4pm.

Whilst we welcome any communication on this topic it should be noted that it is not about euthanasia nor sudden death. It is about experiences and views on service requirements for those living with and dying from any advanced, progressive and incurable condition.

/more

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Paper copies of the questions can be obtained by contacting us at:

Patient and Client Council, Northern Area Office, Houston’s Mill Site, 10A Buckna Road, Broughshane, Ballymena, BT42 4NJ, Tel: 028 2586 3950.

These questions are also available on our website -

www.patientclientcouncil.hscni.net

Remember, the Patient and Client Council is your voice in health and social care.

ENDS

For further information contact:

Patient and Client Council
Houston’s Mill Site
10A Buckna Road
Broughshane
Ballymena
BT42 4NJ
Tel: 028 2586 3950
Freephone : 0800 917 0222
Website: www.patientclientcouncil.hscni.net

