

Citywide Palliative Care and End of Life Plan Engagement Report

Introduction

The North West LEF welcomed over 40 individuals, community group and voluntary sector representatives from across the city to an engagement session on the 30 November 2017 in the Albany Centre to consider and discuss the draft HSCP Palliative Care and End of Life Plan.

In the main, participants welcomed the draft Plan and those present felt it was positive development to raise awareness of an often a difficult and 'taboo' subject. It was felt that it was important to support families to have difficult conversations and plan for the future especially if a family member has a long term condition or has been diagnosed with a terminal illness.

Workshops

The attendees were split into 5 workshops groups and the wide ranging discussions, points and suggestions made were recorded at each of the workshops.

Group 1 - Facilitator/Scribe - Russell Robertson

Do you agree with the key aims set out in Section 2 of the Plan? - Yes

- Paper into practice will be the difficult. Is there enough staff, resources, management, capacity etc to put this plan into practice?
- Good communication between services, agencies and the family is essential.
- Hospital discharge needs to get better – service/care breaks down when a patient goes from hospital to community.
- Service need to be more person centred – think about the families needs and carers being involved and consulted – essential to have a 'care planning' meeting.
- Services/agencies supporting people and families are ignored when a person is admitted to hospital – these service have a huge amount of information and knowledge that could be useful to the hospital/when deciding treatment plan.
- There is a lack of support and services in the community – families are missing out.
- A multi disciplinary integrated team is a good idea.

In section 3 we set out our actions – 'what we will do'. Are there any additional points or actions that need to be considered?

- Third sector – there is a disparity between what HSCP want and what they are able to delivered for the amount of money being paid/allocated.
- Third sector services - who does what?– there needs to be a degree of respect and involvement in decision making and service delivery.

- Third sector worry about sustainability due to the uncertainty of contracts, personal care – contract restraints and time limited contracts. Time limited contracts impact on Cordia, care and home support providers.
- 3rd sector are willing to work closely with professional and statutory providers (GP, hospital teams, housing to get the best outcome and support for patients and families. Better knowledge and sharing on information would influence and shape care as the needs of the individual increases. More trust in the 3rd sector
- What is the role and input of the private sector in relation to palliative care plan
- Need for bigger conversations.

Is there anything missing from the table of priorities?

- Communication with the private sector in their role in this Plan.
- Equipu – needs to be part of the conversation – equipment supplied quicker.
- There needs to be better use of telecare and new technology.
- A named or link person or named care manager would be good to support patients and families to help with accessing services, co-ordination of services and communication.
- Establish better communication between all services involved in someone care – patient, GP, hospital, family, carer, Cordia, 3rd sector providers etc.
- A standardised plan across the city so that you should get access to the same or similar services no matter where you live in the city.

Any other comment or points

- Comeback with outcomes and developments once the Plan has been agreed and implemented.

Group 2 - Facilitator/Scribe - Lisa Martin

Do you agree with the key aims set out in Section 2 of the Plan? Yes

Broadly the 6 group members did agree however added the following comments:

- Good that the plan is aspirational but delivery of outcomes will be hard to match up to that aspiration as services are not equipped/resourced to respond
- Need to look seriously at translation of aspiration into practical application
- Concern about tokenistic consultation
- The language in the draft plan is difficult – not accessible and designed for and by professionals and clinicians – not user friendly

In section 3 we set out our actions – ‘what we will do’. Are there any additional points or actions that need to be considered?

- The section says very little about what will result from the actions - statements that begin with ‘develop our relationship with’ and ‘establish, in collaboration with’ are not helpful as they don’t give detail
- Add an action to review the working relationship between the statutory and third sector carer centres – anecdotal evidence from carer that this isn’t always joined up
- Action to improve information for carers – develop a resource, both online and physical – to include explanations of jargon, medical terminology, summaries of HSCP policy documents and case study examples that offer explanations of different decision making and outcomes aimed at carers
- There needs to be an action to make support services at home genuinely 24/7, out of hours is not good enough

Is there anything missing from the table of priorities?

- Consider an NHS/HSCP non-profit service to supply small aids/adaptations to people without need to wait on OT assessments and to prevent the need to buy commercially
- Each person/family/carer to get an allocated support worker (either from HSCP or from a third sector organisation) to help navigate the early stages of the care journey inc support with decision making and information on services/care/options/choices
- Regulation, monitoring and evaluation by carers and families of services commissioned through SDS/personalisation
- More focus on carer well-being and support

Any other comments or points?

- Generally, information for carers is poor
- Jargon/unfamiliar clinical terms frequently used in documents and by workers
- Understanding the care pathway is still difficult
- Concern that OT services, which are crucial, are not ready to respond to the coming increase in people receiving care at home
- Impact of personalisation on carers – it is often presented as empowering and about choice but many carers find it put them under increasing strain (mental but also physical as they manage more aspects of personal care) as level of service/quality is often not the same
- Carers centres capacity is lower – they are not as visible now
- Rehab services not consistent and often not sure what you are entitled to

Carer experience – ‘the organisation (HSCP) is there for administration, the carer is always there for the person’

Group 3- Facilitator/Scribe - May Simpson

Do you agree with the key aims set out in Section 2 of the Plan? Yes

- It is a positive move that palliative care and talking about end of life plans are on the agenda and being considered and talked about. It should be part of the conversation when doing a care plan, personal plan or an ACP.
- It's important that any plan is reviewed a regular/annual basis as circumstance change – how would this happen if the 'owner' of the plan is the person them self – who what would prompt them to review the ACP/personal plan
- It's a social model of disability/illness/poor health – you talk about the person rather than the illness – this is positive.
- It should involve the individual, carer and family – and it should be person centred/individual. It was hoped that carers were seen as equal partners.

In section 3 we set out our actions – 'what we will do'. Are there any additional points or actions that need to be considered?

- It was felt that we were 're-inventing the wheel' as we used to have specialist nurses that worked in the community – they were taken away and now we are re introducing them.
- There needs to get better links and working together between care providers and services - hospital, GP, SW, Carers services, DN, Housing etc – through sharing information. It's important the patient is at the centre of it – will the ACP do this?
- There is a need to reduce assessment – sharing information would reduce multiple assessments
- People living alone or no family nearby – it would be good to have link worker or advocate that would ensure services were co-ordinated/line of communication were in place at the right time
- Services need to be more flexible to meet the needs on an individual basis
- Churches and community organisation should be part of the ACP – service need to be more aware of what is in the community.
- Housing Associations – what can they do? Is the awareness training going to be extended to include HA staff. It was felt in general the HSCP need to have better links with housing providers
- There is less money about and that is a problem for all service providers – more reliance on carers and families
- Great use of new technology to get ongoing feedback from service users patient and 'hard to reach groups'
- The 'conversation' about palliative care services needs to be ongoing – not just a one off event.

Is there anything missing from the table of priorities?

- It would be good to have a link person/named person (who could be chosen by the patient themselves – similar to power of attorney) – especially for people with no family and live alone. Some to advocate and help co-ordinate services.
- New technology and innovation – for information, providing support/care solutions and monitoring conditions is not mentioned and should be included in the plan.
- Information in the community in accessible and paper format.
- Training and greater awareness of ACPs' and palliative care service for key staff and partners including staff in residential and nursing homes, Housing Associations, Cordia, re-enablement teams and 3rd Organisation.

Group 4 - Facilitator/Scribe - Janet Hayes

Do you agree with the key aims set out in Section 2 of the Plan? - Yes

- General agreement with the aims set out in the plan

In section 3 we set out our actions – ‘what we will do’. Are there any additional points or actions that need to be considered?

- What about people on their own? They may slip through the net if no one there to ensure appropriate services in place for them.
- Not anything in the plan particularly around special needs/learning disability
- What about Palliative Care Transition Plan – children to adults?
- Need to be sensitive to different needs
- Trained staff to take feedback: could staff be trained to listen to patients and ‘vocalise’ any concerns they may have, listen and act on information. This is similar to ‘Teddy’ Hospital initiative at Children’s Hospital as this allows a safe place and time to speak to individuals.
- ‘Realistic Medicine’ – a two way conversation re what’s good for you that takes place with clinicians and professionals – similar to ‘what matters to you’
- Could we have a Practitioners Guide re asking right questions – there is a UK example – and this could be available in different languages etc
- Confidentiality is an issue as difficult for neighbours, friends, community to find out if someone needs help. Who is told about those who are sent home?
- There is a misconception re palliative care – clarity re what it means and covers. Could get greater input from carers/other organisations if we apply standards and learning
- Revise some of the language in plan i.e. what do we mean by ‘community/communities’
- How do we know this is working – measures to demonstrate/milestones/outcomes
- Need to have education around individual’s rights and how to get this information out
- Could case studies be used to describe what can be offered when looking at a plan?

Group 5 - Facilitator/Scribe - Tony Devine

Do you agree with the key aims set out in Section 2 of the Plan? Yes

- Very supportive of the newly created role of co-ordinator who job is to liaise with professional groups - **they should also speak to people who have received the service and family members.**
- Hospices should be consulted as they build good relationships with families and practical knowledge gained.
- It is important that health social care staff liaised with Hospice staff as this reduced the amount of information they had to get from patients and family members leaving them more time to deal with patients.

In section 3 we set out our actions – ‘what we will do’. Are there any additional points or actions that need to be considered?

- **Communication between providers needs to be improved**
- They felt it was important that patients received information and were involved in any discussions about their care and treatment.
- Aids and equipment should be collected from patients home as they had passed away - some examples given of the difficulties experienced by family when they tried to return equipment to service providers.
- Probably the most important point was that care package must be fully in place when people left hospital.
- Examples give of **staff putting patient and family under pressure** with questions like can a family member do this, can one of your friends help what about one of your neighbours.
- Some patient’s partners are elderly and have their own health conditions they have to manage family members live far away, neighbours not always willing to help.
- Other comments Will Brexit reduce the numbers of staff available to work in the care services sector?

Is there anything missing from the table of priorities? No

Next Step

The points recorded at each of the workshops will inform and contribute to the final draft of the Plan along with the feedback and comments gathered through the online HSCP consultation survey and at the various engagement sessions with key service providers and stakeholders.

December 2017