Healthwatch Stockport End of Life Conversation

29th January 2019

Inform. Involve. Influence.

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End of Life Conversation

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Task Group: Maria Kildunne, Maqbul Rose, Gerry Wright, Nicole Alkemade, Jo Keyes

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1. Executive Summary

It is with a full heart I write this summary and I am humbled to have been part of this End of Life Conversation. Real experiences and the stories of some were heart breaking. However, through their determination to make it better for other people they were willing to come out on a cold snowy day in January to give us their time and company.

For many, the end of someone's life is often difficult to talk about particularly before the person has passed away. Why it is still a taboo subject for many is probably the fact that it is so difficult to envisage losing the people we love.

To help improve access to care and support services people need at such an emotional and intense period, it is vital that we raise the issue and keep talking about end of life and long before we think its near!

This report provides feedback from people who have had experience with end of life care, always involving a loved one. They told us their stories, what worked well and offered solutions to what could have been improved at this precious and difficult time in their life.

Feedback from the consultation will inform the development of the new model. We hope it will also complement the engagement already carried out with staff teams across the sector undertaken by Stockport Clinical Commissioning Group [CCG].

25 people contributed to the End of Life Conversation, 17 people attended the afternoon tea event and more joined in other ways. It was an informal and relaxed atmosphere, afternoon tea was served and 2 groups were formed to discuss some general questions about their experiences.

In the first session participants talked generally about what worked well and not so well for them, providing reflection and thoughts on what could have improved their experience.

The feeling about service provision was that it is generally poor and uncoordinated. Professionals, on the whole are caring and there was an acknowledgment they are often over worked and there was no doubt they want to spend more time with their patients.

However, it is felt they often do not know how to talk openly about the subject and know at what stage in end of life care to start to talk about dying. There is a lack of a person centred approach and lack of communication came up throughout.

There is lack of support for people with disabilities and in particular sensory impairments. Carers do not feel well informed of other services that are available to them. They feel more support during bereavement would have helped them.

However, there are some pockets of really good practice particularly from the respite team and local voluntary organisations, which if invested in could really help with training needs and support respite for carers. These organisations could also help with coordination of services.

Dementia and the support required for people with dementia and their carers came up a lot in conversations.

In the second session Nicole Alkemade, Commissioning Manager for Dementia, Stockport Clinical Commissioning Group and Jo Keyes, Macmillan Head of Palliative Care and End of Life, Stockport NHS Foundation Trust, provided the group with a proposed draft model for end of life care to improve services. Based on the feedback and discussion from session one, they agreed that changes were needed and would be implemented.

All in all it was a really productive session. I would have liked to have seen more people representing different faiths and cultures and backgrounds to see what we could learn from each other. I would also welcome more views of people with long term conditions, disabilities and mental health issues.

I fully recommend you read the quotes from participants in Appendix iii. as it really brings home how important it is to get end of life care right.

I look forward to re-joining the people who came to our conversation in the autumn to see what has happened as a result of the input from local people.

If you would like to join us for our autumn session please get in contact with us here at Healthwatch Stockport.

We hope that the recommendations proposed in this report are considered seriously and feedback is given to the participants involved in the conversations.

We hope to keep the conversation going…

‘We’ve been doing it for thousands of years and we still haven’t got it right!’

[Participant in the End of Life Conversation]

Maria Kildunne
Chief Officer
Healthwatch Stockport

2. Introduction

Usually people who are approaching the end of life are those likely to die in the next 12 months[1].

End of life care helps all those with advanced, progressive, incurable illnesses to live as well as possible until they die. It enables the supportive and palliative care needs of both person and family to be identified and met, through the last phase of life into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.[2]

Palliative and end of life care services are delivered by a range of providers and teams across Stockport. These include NHS services, social care and the voluntary, faith and independent sectors.

The recent formation of integrated neighbourhood teams has addressed some of the duplication of services for patients, but some silo working still exists with a lack of coordination for people who are in their last year of life.

Changing demographics means that there will be more people living and dying with multiple conditions, at the same time as having less family support locally. To meet these changing patterns, new ways of planning for and designing services for end of life need to be found, or there is a risk that many more people will not receive the care they need.

Stockport CCG and Stockport NHS Foundation Trust recognise that end of life care is a serious commitment which involves both patient and carers, they want to find ways to improve care, to closely meet their needs and preferences and to empower them.

Therefore, Stockport CCG plans to commission a new model with an aim to:

Provide a high standard of person centred care to people who are approaching the end of their lives, including support for the people who are important to them;

by developing an integrated care delivery model that is coordinated, flexible and can meet the holistic needs of patients and families, to give them the best possible chance to live well in their last stage of life before dying with peace and dignity in their place of choice.

'End of Life' pathway improvements were identified via a SWOT [Strength/Weakness/Opportunities/Threats] analysis by service providers and commissioners. To ensure local people are involved and their voices heard, information gathered from the End of Life Conversation with Healthwatch Stockport will further inform the analysis and lead to a new model of care [see proposed future model in appendix i].

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[1] General Medical Council ,2010

[2] Source: National Council for Palliative Care, 2006

3. Methodology

Healthwatch Stockport were approached by Stockport CCG and Stockport NHS FT, who made us aware that a review was taking place around end of life care plans and asked if we would be interested in taking part and helping to facilitate the views of local people who may have had experience of palliative and end of life care.

Following approval from Healthwatch Stockport Operational Team, which included an appraisal of our current work programme priorities, a date was set and the End of Life Conversation was promoted.

Promotion of the conversation was carried out via social media, circulating and displaying posters via our contacts and directly contacting local voluntary organisations and community groups to invite people who have experience of end of life care.

A total of 25 people contributed to the conversation. 17 people attended the event, a small number of people were unable to attend the event and so feedback was gathered electronically and we attended a group of carers for people with learning disabilities. [For further demographic information see Appendix ii).

The End of Life Conversation Event which took place on 29th January was split into two sessions.

Session one:
Participants were split into 2 discussion groups.

Opinions, comments and suggestions of participants were facilitated using an informal interview technique, in small groups. Each group discussed 4 broad questions;

1. **[in your experience of end of life] What support did you use and how useful was it for you and the person you cared for?**
2. **What did you find challenging? What gave you extra stress?**
3. **What did you miss? What didn't work well? What can we do better?**
4. **Were your needs assessed? What are your needs at the moment and what support do you receive?**

(For in-depth opinions and comments to these questions see appendix iii).

The responses from the discussions were recorded then summarised on to a flip chart under the headings 'strengths, weaknesses, barriers, challenges, good, bad and other' (see appendix iv).

Session Two:
The summary feedback gathered in session one was used to inform the start of session two.

Nicole Alkemade – Stockport CCG Commissioning Manager for Dementia, Frailty & End of Life and Jo Keyes - Macmillan Head of Palliative and End of Life Care from Stockport NHS Foundation Trust gave a run through of the feedback from participants and then provided a presentation of the proposed draft 'End of Life Care Model'. Participants had a copy of the draft model to view as part of the presentation and had the opportunity to ask questions during the session.

An aim of the conversation was to create a secure space for participants to feel comfortable in sharing their experiences within their group. In the past Healthwatch Stockport have used small group/afternoon tea style sessions which have proven to work in enabling people to feel relaxed about putting forward their views.

4. Findings

For full details of the conversation including quotes from participants please see appendix iii.

Overall the conversation was engaging and participants identified issues of concern which mainly included the following:-

i) There appears to be an uncoordinated approach to palliative and end of life care by professionals i.e. General Practitioners, District Nurses and employed carers

ii) Professionals often do not begin or include the initial end of life care conversation with the patient and/or carer

iii) Carers and family members often feel that they are not listened to in relation to patient care

iv) Patients 'holistic needs' are not being met as Care Plans are not developed soon enough and are not patient centred

v) People need more support during and after their bereavement to help address isolation, financial issues and wellbeing

vi) There is a real concern for the care of patients who are deaf and have learning disabilities (also in circumstances if their carer dies)

vii) Social Workers (and those employed as part of the Respite Team) are seen to be providing a good service, when they are knowledgeable and experienced

viii) The care setting is important as the quality of care provided differs depending on the setting

5. Conclusion

This report demonstrates clearly that the current model of practice for palliative and end of life care is not fully suitable to meet the needs of patients and carers in Stockport. Whilst there are pockets of really good examples of practice, this is not consistent throughout Stockport.

Communication, Coordination & Support
People at the end of their life and their carers **need** conversations earlier about the care, treatment and services available to enable them to be part of the decision making process. Key to this, is knowing who will start the conversation, open up this dialogue and begin a person centred approach to care planning.

The findings ascertain that **primary care** has a significant role in **leading** the way in terms of coordinating and organising end of life care and ensuring statutory organisations across health and social care are working in partnership to support the family and carers throughout the process.

The **voluntary and community** sector have a very significant role in providing information and practical support for all involved at end of life and should be part of the partnership and resourced adequately to do so.

This is what local people tell us they want to happen.

Care Planning
Early conversations need to be had at the most appropriate time to develop **'person centred'** care plans. To initiate this process, GP's need to feel confident and comfortable 'opening' the end of life conversation (preferably immediately after diagnosis if relevant).

There is a lack of knowledge, understanding and time constraints with other health professionals i.e. carers (in all settings) and district nurses. Their roles and responsibilities need to be clarified further to ensure patients' needs are met and family carers receive the training they need to provide suitable care.

The care setting is of the upmost importance. It appears that care and processes are rushed towards the very late stages of end of life care, resulting in **unplanned emergency admissions** to hospital and care homes, which could have been avoided with more family input and care planning. This then raises the question about people preferred wishes on where to die.

There may be the need to have a **full review and refresh** on how care plans are started and developed for people in Stockport.

Training on what palliative and end of life care is, was found to be useful by carers and could include **information** on the type of support and treatment available, especially if the patient is living with other conditions e.g. Dementia.

Frontline staff need continual training and updating on end of life care.

Vulnerable Groups

During the Conversation there were concerns noted for support for the provision for deaf people and those who have learning disabilities (especially if their carer died) and people living with motor neurone disease.

Some services received praise i.e. the Respite Team, the Rapid Response Team (especially the care workers in the team) as well as individuals i.e. Consultant in Palliative Care, Speech and Language Therapist and the Palliative Care Sitter. However, it was often down to the experience, dedication and knowledge of the particular worker or carer as to whether people's experience was good or poor and it was not consistent.

Carers' Needs

The effects on the carer can be **considerable** in relation to the extent of physical and emotional overburden as well as difficulties in covering care-related (including home adaptations) costs among family carers of people at the end of life.

Therefore, it is pertinent that the **carers needs'** are addressed also as they are providing the 'holistic' care that patients need in their preferred place of death. Also with regard to carers health the systems inability to allow carers to 'book' respite care in advance was acknowledged and it was thought that this therefore, did not meet the needs of carers. Carers have useful information about the patient's needs 'and want to be seen **as a valuable partner for care** which would provide a more positive patient care outcome.

Bereavement

There was a lack of understanding and/or a gap in provision of the needs of grieving carers. Coping with the loss of a loved one, along with the **loss of identity and often purpose** after caring continually for a significant period of time can leave carers feeling isolated and unsupported.

Therefore, information of bereavement services are valuable in care settings. An example of this is the **'Bereavement Programme'** at Beechwood Cancer Care.

It is clear that there needs to be a consistent, integrated approach with co-ordinated services for palliative and end of life care. This has to be achieved within a locality with an ageing population and **challenging financial context**.

Consequently, this proposes major challenges for Stockport CCG as GPs and other health and social care providers will be expected to do more, with less resources. Alongside this challenge, there is a commitment to meeting patients' preferences about how and where they wish to be cared for at the end of life, and providing the resources to allow a greater proportion to receive care and die at home.

The findings from the conversations highlight a number of themes in improving the provision and organisation of high-quality end of life care:

i) **Co-ordination of care** and **communication** across health and social care professionals

ii) **Communication with patients and carer** about the prognosis and **care planning** (care plan)

iii) **Bereavement care** and minimising the health care risks of carers

iv) **Training for staff and carers** involved in palliative and end of life care

v) Provision for **carers**, **deaf people,** people with **learning disabilities** and other vulnerable groups

vi) **Respite and Rapid Response Teams (Enhanced Care Team) provide a very good service**

vii) **Consultants are regarded as providing good support but later on in the process**

6. Recommendations

Coordination, Communication and Information

i) Develop a professional co-ordinator role to have contact with patients and carers and help to co-ordinate appropriate support services

ii) Utilise and invest in the skills and expertise of the voluntary and community sector to help with above coordination, respite and support

iii) GP's to be provided with the following support:-

Information on support services for palliative and end of life care

iv) Further engagement work to be undertaken on people's preferred place to die and the care setting people are in prior.

Needs of protected groups

v) Improve provision for profoundly deaf people and people with learning difficulties to ensure new model meets their needs

vi) Undertake further engagement with people from black and minority groups

Training

vii) Mandatory training for care staff and other professionals involved in palliative and end of life care (to include information on all support services that is available to those being affected). This might include a mapping exercise to find available support services

viii) Training for healthcare professionals to have knowledge and understanding of when and how to start end of life care conversations with patients (carers and family), especially if a patient is suffering from Dementia

ix) Training opportunities and updates for people in an informal caring role and clarity of health professionals roles i.e. district nurses capacity to provide end of life care training support to carers and family e.g. PEG Feed and treatment

Care Planning

x) Review and refresh of care planning approaches in health and social care

Ambassadors

xi) [For Healthwatch Stockport with support from CCG/Stockport NHS Foundation Trust] identify End of Life Care Champions to facilitate conversations in local group to keep the conversation going. Incorporate good practice from local organisations as well as national charities and organisations such as Hospice UK and the collaboration 'Dying Matters', The National End of Life Care Programme and The National End of Life Intelligence Network. We commit to holding a Network Event during Dying Matters Awareness Week in May 2019.

7. Next Steps

i. Briefing from Stockport CCG and Stockport NHS Foundation Trust in Autumn 2019

ii. Report to be published and disseminated to relevant organisations and groups [see appendix vi]

Note from the End of Life Care Leads:

"A true reflection of the conversations which took place, really well written, touching and provides clear guidance what is needed next. We want to get it better for people currently in the position of losing a loved one, and we will demonstrate that we listened to their comments by a acting upon the recommendations. We thank Healthwatch Stockport for their support with this piece of work. It is great working with you!"

Nicole Alkemade and Jo Keyes

8. Acknowledgments

We would like to thank all the people who took part in the Healthwatch Stockport End of Life Conversation, your views will help to shape future services, improve the health and wellbeing of the local community and reduce inequalities for all communities. We know it has been a difficult subject to talk about but you have helped start the conversation and let's continue to do so.

Thank you to Nicole and Jo for inviting Healthwatch Stockport to help gather people's views.

Thank you to members of our Enter and View Team who helped facilitate and contribute the Conversation.

[Thank you to the Healthwatch Stockport Reading Group for proof reading the report and responding with many suggestions and advice.]

The support of all of our stakeholders has been invaluable.

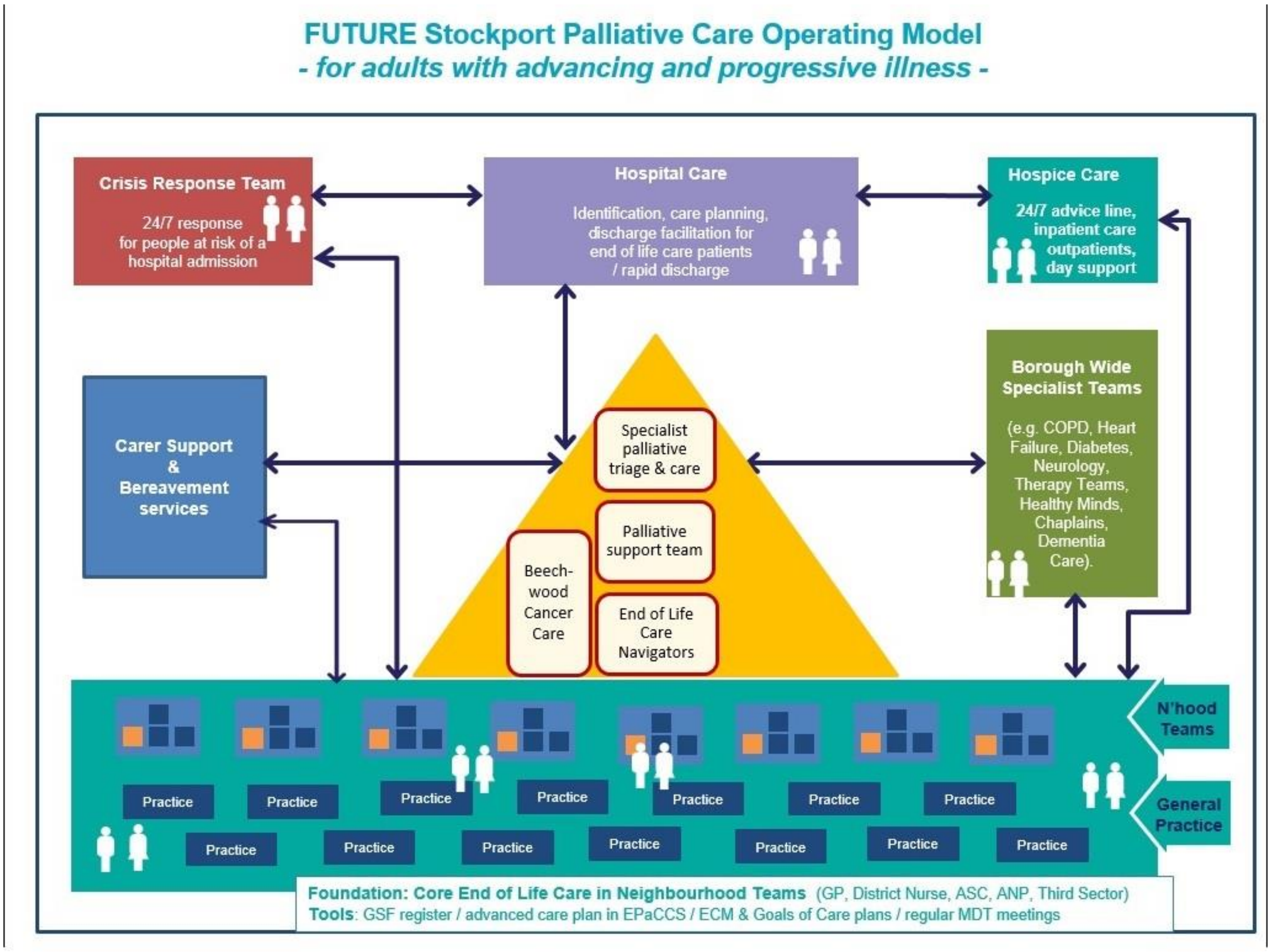
9. References

With the End in Mind (Kathryn Mannix, Dec 2017)

We need to talk about Death (Horizon, Jan 2019
(https://www.bbc.co.uk/programmes/p06yc17v)

10. Appendices

Appendix i) Proposed future model of care



Appendix ii.) Demographic Information

Geographical area :	Ages:	Disabilities:	Carers: EOL Care
All Participants [25] came from across Stockport in postcodes SK3-SK8 and just outside Stockport in SK12	All participants were over the age of 30 with the majority being over the age of 65	5 participants stated that they had a disability	All participants have/had a caring role in terms of end of life care
Gender:	Sexual Orientation:	Relationship Status:	Employment Status:
Participants were a mix of male and female with the majority being female	All participants [who answered this question] stated they were heterosexual	All Participants were either in a long term relationship or married. Some were now widowers	Only 2 participants were currently employed. The majority were retired.
Ethnicity:	Religion:	Additional notes	
ALL [who answered this question] WHITE BRITISH	ALL [who answered this question] stated they were CHRISTIAN		

Appendix iii) Detailed Findings to the Questions used in Session One

The conversation identified a number of key findings as summarised in section 4. The following information outlines more detailed analysis of the data collected including the conversation in session one. Many of the responses apply to more than 1 question; however the findings have been separated under each question to provide clarity.

Question 1. What support did you use and how useful was it for you and the person you cared for?

Support has been separated into two areas for the purpose of this report a) information for carers and b) services.

a) Information for carers

The focus groups experience was that the information if received, was very ad-hoc. Some responses indicated that it came too late and was very difficult to access as stated below:

Carer of husband (deceased)

"Support came too late and information was hard to find …and some support was good with the Consultant in Palliative Care, didn't come soon enough though, but the things that he put in place helped."

Participants felt that this area required great improvement as it became evident that timely information is needed to aid them through a complex and emotional situation. Carers need to know what support is accessible and when; and need this information before palliative care begins and to continue into end of life care (this should include information on what palliative and end of life care is and on the type of support and treatment available, particularly if the patient lives with other conditions e.g. Dementia or Motor Neurone Disease).

A response supporting the above:-

Carer of mum

"Someone (End of life Care facilitator) came in and did a talk and it was really good. There was quite a few relatives there so it was quite enlightening in terms of what to expect (with palliative and end of life care)

b) Services

The focus group discussed 'care for patients' in various settings including patients' homes. It was recognised that the quality of care provided depending on the 'setting' and the health professional providing the care. A total of 15 services were discussed which received positive and negative comments.

Carer of husband (deceased)

"It (support) depends on the setting, where the person is….whether they're at home, in a hospice, in a hospital or in a care home…and the experience is very different in each."

Discussions indicated a lack of palliative and end of life care **understanding** and support in terms of treatment and information from GP's and district nurses (see Case Study 1). Issues that raised concern were recognising when the patient may be approaching end of life and to provide appropriate treatment, timely advice and support for the patient **and** carer.

Case Study 1 – Highlighting inadequate information, advice, care and support.

Mum was deaf and lives with osteoporosis and osteoarthritis. She had lost her sight in one eye and the other was deteriorating with macular degeneration. Daughter gave up work for 11 years and looked after her in her own home until 2 weeks before her death, as mum could not do daily jobs (couldn't look after her house or garden). Mum was also deaf and therefore her daughter was her facilitator and was happy with this situation.

But daughter did not realise that the situation would become unmanageable and by then it was too late. There was no other family and mum was a very shy person. ***In hindsight her daughter wished carers had been bought in at an earlier stage but she did not know about support offered. GP visited her mother but did not suggest any support.***

The Rapid Response Team were sent in twice as mum became very poorly over Christmas (2016). All the signs for end of life were present, sleeping, not eating etc. The GP visited before Christmas and the Rapid Response Team were sent in as she did not want to send her to Stepping Hill.

The Social worker recognised that daughter was not coping and got her mum into a care home for respite. Mum would not stay in the care home and returned home after she recovered.

Mum became very poorly again and the Rapid Respond Team was sent in again and nurse queried with the daughter as to why the GP had not discussed palliative care with her. In that period, mum gradually deteriorated and would scream at her to kill her. Daughter couldn't bear it anymore and felt that no one gave her any support to help her mother.

District nurses only came to give her injections for a vitamin deficiency. *At the end, mum wanted to die at home and daughter provided 24 hour care and was finding it difficult to continue the care.* ***The Social worker didn't know it wasn't possible to book care.*** *Social worker was the only one who tried to do something.*

Having paid support was not a barrier to accessing care as mum was self-funding; ***daughter did not know where to go to get help and didn't know about the support her mother would need during the palliative and end of life stage.***

The case study above identified a key concern for the focus group and that is the provision for deaf people and for those who have learning disabilities as identified via consultation with the Carers for Learning Disabilities Group who posed the question below:-

"What can you do when a carer passes away, who is looking after someone who has learning disabilities? Do you get a key worker with specialist knowledge?"

Proposals for adaptations to the home caused stress due to financial constraints and to the extent of the adaptations whilst caring for a loved one/patient. There is a need for services to share information to understand families/carers situations and therefore, be able to provide support with relevant assistance i.e. information on grants.

Carer of husband (deceased)

"The other thing wasn't good because the man who came, he was like a hurricane through my house. You'll have to rip that out, rip this out, do this, do that, and it was…cost me an arm and a leg. I couldn't do it. It was impossible to live in while it was done...."

However, some services were praised including some Borough Care Homes, Hospice Care, Social Services, The Rapid Response Team, the Palliative Care Sitter and the Speech and Language (Therapist) Service.

It is clear that there needs to be a consistent approach for palliative and end of life care so patients and carers know when and what information, support and services they can access and by whom. This allows carers to support their loved ones to make informed choices and receive better care.

Carer of husband (deceased)

"I was never given any specific information, nobody discussed palliative care……. I think it's down to communication and information and obviously if you are doing an end of life plan and (want it to include) peoples wishes, they'd have to be aware of the need to make that decision before they lose their faculties"

Niece of Auntie (deceased)

"Auntie was in a very nice care home and was put on end of life drugs. The day before she died I was begging for the Doctor. Got to the point I rang the Social Worker and said I would walk out if I didn't get any support. She got her into a care home and it was awful, it was dreadful. I couldn't even leave mum for 10 mins. She was screaming, she must have been so frightened. They called the GP, she was in a bad way and GP would not prescribe medication. She died less than 24 hours later. This could have been avoided."

Carer of mum (deceased)

"But the difference between the carers and the nurses on the Enhance Support Team was miles apart as Rapid Response Team were wonderful".

Carer of husband (deceased)

"Got some respite which was good…he went into a Borough Care Home……….that was good cause that was my time. I got some counselling which was so so…I had a palliative care sitter…that was great. Another person who was excellent (Speech and Language Therapist)".

Question 2. What did you find challenging? What gave you extra stress?

The focus group identified many challenges about end of life care that caused stressful situations and in particular, when an end of life conversation should start; by whom and not knowing what should be included in the conversation. If a patient had Dementia this further complicated the situation as it is difficult to determine by carers **when to have the end of life care conversation.** Care plans were not developed properly and/or implemented well due to lack of **'open'** conversations between carers and/or patients and health professionals and therefore personal choice for the patient and carer was often disregarded.

Carer of mum

"Wished I had some conversations with my mum earlier about what she wanted, but because however much I know that you should have a conversation about what you want to happen when you die…………..to talk to my frail mum who (with dementia), …it's a conversation that I just found too difficult to have."

Responses indicate that participants (carers) **needed** conversations earlier which would allow care plans to be implemented, so that the choices identified by the patient and relevant family members would be adhered to. Care plans would support carers and patients when unforeseen situations arise as in Case Study 2. There was a misperception about **who** should start the conversation and that GPs were reluctant to, *"GP could not say end of life. Did not want to have that conversation"*. This caused great distress as in any situation whether emotional or physical, the family GP is the first point of contact, and it was agreed that the conversation should be initiated by a healthcare professional.

Case Study 2. *Granddaughter regarding her Nana with Alzheimer's highlighting the need for an in-depth care plan*

Nana was in a nursing home that the family were very happy with. However, upon inspection by a GP, the GP advised that her nana should go to the hospital due to dehydration.

However, the son and granddaughter knew that she was coming to the end of her life as she was showing symptoms. The son called his daughter as the ambulance men arrived to take her nana away.

The granddaughter almost had to argue with the paramedics so that they would not remove her *from the care home (Nana could not speak for herself but she felt that her dad wasn't quite strong enough; he would have let them take her to hospital although that was against his wishes cause he felt that somebody professional was telling him that was where she needed to go).*

Case Study 2 also highlights the **trust** carers put in professionals especially during a period when they are feeling vulnerable. In this case the granddaughter professionally worked in a service that provided support to vulnerable patients and therefore, had the confidence and knowledge to make the families' choice be heard and understood. Health professionals need to be sensitive to families' vulnerability and take the time to have conversations with families and patients in an appropriate way.

Participants felt that care plans did not meet the needs of patients and did not reflect 'person-centred' care that should meet the patients' spiritual, psychological, cultural, religious and physical needs. Comments made by carers identified that carers wanted a holistic healthcare approach:-

Wife/carer of husband deceased

"Care plan was not put in place properly. Because they wanted things that he didn't want and there was a bit of a disagreement about it. One thing I did want to point out is when you talk about talking to people about their wishes and it talks about holistic care, spiritual care ……I don't remember any of that. No one talked to him about his wishes"

Valuing people as active participants and experts in the planning and management of their own health & well-being ensures that the outcomes and solutions found have meaning to the person in the context of their whole life, leading to improved, successful support for them. Having a conversation with a patient and their carer/family about death is a difficult conversation to have. Methods need to be put in place to **enable** GP's to 'open' the conversation and start a dialogue with the carer/family which will then inform the development of personalised care plans.

Daughter carer (mum with dementia)

"I think it's particularly difficult with a diagnosis of dementia (to have the conversation) because it can go on for absolutely years (mum was 15 years). Everyone's journey is different with Dementia and that's what makes it tricky."

Question 3. What did you miss? What didn't work well? What can we do better?

This section discusses GPs and other professional staff (including carers) skills, knowledge and understanding of palliative care and EOLC.

Participants believed that due to staff changes and time that staff were not trained well enough staff to support palliative and end of life patients.

Experience in specialised nursing home (2 years)

"Found it to be a good and bad experience. ***It depended on carers, medical staff, it depends on their knowledge.*** *Find that people who had experience of caring for somebody with dementia, obviously they had a lot more knowledge than you had and a lot of the untrained staff, both in the nursing homes and in hospital expect someone to say 'are you not hungry' (to their loved one) which is why I was going in every day. A training programme was set up at Stepping Hill but staff change all the time, medics don't always have the time to do that training".*

In the comment below, it is clear that the carer required further training, but this was not implemented due to 'time restrictions':-

Wife of husband (deceased)

"My husband ended up in a nursing home because, main reason, there was no district nurse who had the time to show me how to use the Peg Feed (just shown once) and because he needed that he ended up against his will in a home and he wrote down ***I'm just a lump of meat****, because there was no care personal to his conditions. He was just washed, cleaned, toileted and fed. That was it. Full-stop."*

It is clear that the focus group felt that there is a need for further training in palliative and end of life care for health professionals i.e. GP's, carers and district nurses. There was uncertainty about roles and therefore, carers and patients expectations in terms of care were unmet. Staff capacity is an issue also as well as training for relatives as explained earlier in the report under Question 1.

Carer of Mum

"Meadows is what it is. She (mum) was admitted and me and my daughter were sat there and they said "your mum is here to die, we won't be giving her any medication, no IV. So basically she lasted for 2 weeks. When questioned about given treatment for comfort/pain in palliative care she responded, "She was given nothing, they didn't give her the syringe driver or anything".

Question 4. Were your needs assessed? What are your needs at the moment and what support do you receive?

Participants discussed their needs as carers and want to be regarded as useful with valuable information and understanding of the patients needs and care:-

Wife of husband (deceased)

"Treating the carer as a person with a brain and as someone who has knowledge...I found I suddenly didn't exist (when husband forced into nursing home)".

Also, a significant concern for the focus group which was repeated by many was the lack of support for carers during bereavement as mentioned below by a carer (also in a professional capacity):-

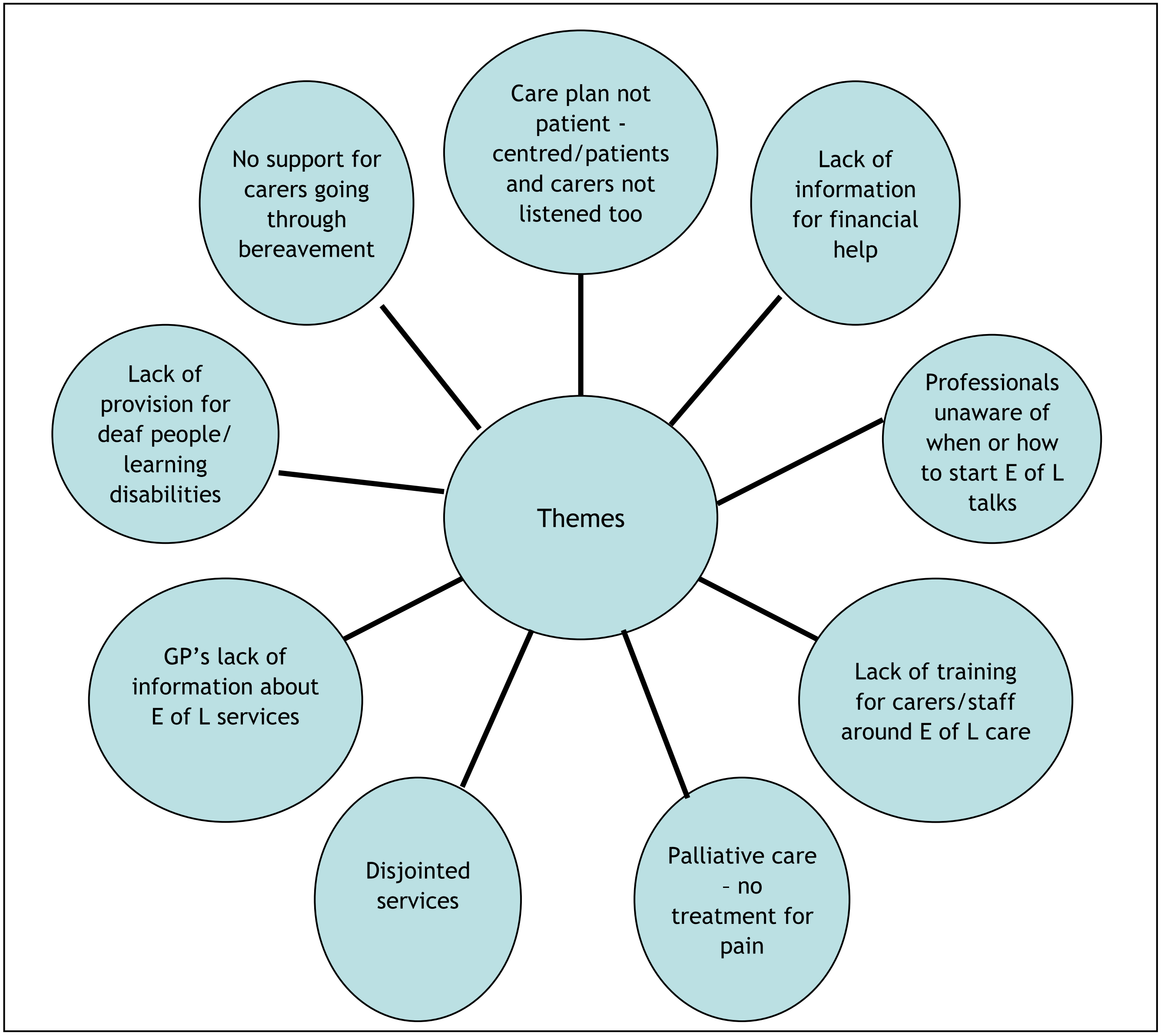
"There's a massive need once that 24/7 carer role comes to an end. A carer once described it to me ***that she felt like she was on the edge of a mountain and about to fall off****. All the services that they had got, all their friends were related to the illness. People lose their own identity as a carer."*

Other needs identified was the systems inability to allow carers to 'book' respite care and responses via email replicated the views of the focus group to have a named responsible worker as well as the points below:-

- Ensure the main relative carer keeps a diary of official visitors and a brief note of the visit (nursing notes usually only relate to nursing procedures) to support with End of Life Grants.

- If possible to make very early contact with the Local Hospice

Appendix



iv) diagram of themes

Table 1 showing outputs from discussion

End of Life Care Experiences Feedback	
Strengths • Rapid Response Team • Assessment of EOL patients by facilitators • Enhanced Care	**Weaknesses** • Not a person-centred care plan • No booking' of respite care • Enhanced care only for 2 weeks
Challenges • Stressful adapting home (financial burden) • Starting EOL conversations earlier • Carers going into homes not skilled/equipped	**Barriers** • Disjointed services • Lack of support from GP's • Lack of training for carers
Good (be done better) • Advance planning (especially with people with Alzheimer's) • Knowing when to start EOL conversation • Being able to have an 'open' discussion about EOL	**Not so good** • Provision for deaf people • Receiving information regarding support and services available • No support for carers during bereavement

Appendix v) Detailed Conclusion

The findings ascertain that the current model of practice for palliative and end of life care is not suitable to meet the needs of patients and carers in Stockport. Carers and patients **need** conversations earlier about the care, treatment and services available to enable them to be part of the decision making process. Key to this, is knowing who will start the conversation as the participants prefer a health professional to open this dialogue (but feel GP's are reluctant to).

The research findings presented here demonstrate clearly that it should be somebody's responsibility to co-ordinate patient care. Primary care has a significant role to play in delivering and organising end of life care. Currently end of life care is managed by a variety of health and social care professionals, but primary care could play an important role in leading the co-ordination of patient care, providing support to patients and carers, the practicalities of prescribing and verifying death, and in follow-up and bereavement care. The voluntary and community sector have a very significant role in providing information and practical support for all involved at end of life and should be utilised and resourced adequately to do so.

Early conversations need to be had to develop 'person centred' care plans and to initiate this process GPs need to feel confident and comfortable 'opening' the end of life conversation. They require time and support to do this effectively and given information on support services and training.

This lack of knowledge, understanding and time constraints progresses further down the care pathway with other health professionals i.e. carers (in all settings) and district nurses. Their roles and responsibilities need to be clarified further to ensure patients' needs are met and carers receive the training they need to provide suitable care e.g. how to use the PEG Feed. Training on what palliative and End of Life Care is was found to be useful by carers and may entail information on the type of support and treatment available, especially if the patient is living with other conditions e.g. Dementia and Motor Neurone Disease. It would be useful to have similar mandatory training in relevant primary, secondary and tertiary care services. There was also a concern for support for the provision for deaf people and those who have learning disabilities (especially if their carer died).

Some services received praise i.e. the Respite Team, the Rapid Response Team (especially the Social Workers in the team) as well as individuals i.e. Consultant in Palliative Care, Speech and Language Therapist and the Palliative Care Sitter.

The effects on the carer can be considerable in relation to the extent of physical and emotional overburden as well as difficulties in covering care-related (including home adaptations) costs among family carers of people at the end of life. Therefore, it is pertinent that the carers needs' are addressed also as they are providing the 'holistic' care that patients need. Also with regard to carers health the systems inability to allow carers to 'book' respite care in advance was acknowledged and it was thought that this therefore, did not meet the needs of carers. Carers have useful information about their patient needs 'and want to be seen as a **valuable partner in care** which would provide a more positive patient care outcome.

There was a lack of understanding of the needs of grieving carers who not only loose a loved one, but also their identity. Caring for the patient takes over a carer's life and once the patient has died, many carers feel at a loss of what to do and their wellbeing may deteriorate. It was discussed that some people may feel that *their* lives may feel empty and they are without a purpose. Therefore, information of bereavement services would be valuable in care settings. An example of this are the 'Bereavement Programmes' at Beechwood Cancer Care which only 2 members of the focus group had accessed as others were unaware of the service.

It is clear that there needs to be a consistent, integrated approach with co-ordinated services for palliative and end of life care. This has to be achieved within a locality with an ageing population and challenging financial context.

Consequently, this proposes major challenges for Stockport CCG as GPs and other health and social care providers will be expected to do more, with less resources. Alongside this challenge, there is a commitment to meeting patients' preferences about how and where they wish to be cared for at the end of life, and providing the resources to allow a greater proportion to receive care and die at home.

Appendix vi) Dissemination

This report will be distributed to the following:

[ ] Participants who contributed to the End of Life Conversation

[ ] End of Life Strategy Group

[ ] Palliative care providers

[ ] Clinical Commissioning Group Governing Body

[ ] Stockport NHS Foundation Trust [Palliative Care Team]

[ ] Pennine Care Foundation Trust

[ ] Viaduct Health

[ ] Adult Social Care & Health Scrutiny Committee

[ ] Health and Wellbeing Board

[ ] Stockport Adult Safeguarding Board

[ ] Stockport Council [Commissioners, Quality Team]

[ ] Stockport Neighbourhood Care

[ ] Care Home Forum

[ ] Domiciliary Care

[ ] Care Quality Commission

[ ] Healthwatch in Greater Manchester Network

[ ] Healthwatch England

[ ] Voluntary Organisations [state which ones]

> Walthew House, Beechwood Cancer Care, Age UK Stockport, Disability Stockport, Alzheimer's Society, Dementia United, Macmillan Greater Manchester [mc.userinvolvement@nhs.net], Signpost for Carers, Stockport Advocacy, CALD, Stockport Educate, BHA and generically through Synergy & Sector 3.

[ ] Healthwatch Stockport website **www.healthwatchstockport.co.uk** and social media sites

Appendix vii) - About Healthwatch Stockport

Healthwatch Stockport is the **independent champion** for people who use health and care services in our Stockport Community.

We provide **information** about health and social care support and services that **works for you** - helping you **stay well**

We gather **your views** and ensure **you are listened to** about what works well and what could be improved

We **Influence** the planning and delivery of local health and social care services based on **your views**

Healthwatch Stockport has been given powers in legislation to help us carry out our role. These include being able to:

- Enter & View places where publicly funded health and social care takes place;
- Promote and support local people to be involved in monitoring, commissioning and provision of local care services;
- Obtain local people's views about their needs for and experience of local care services;
- Tell agencies involved in the commissioning, provision and scrutiny of care services about these views;
- Produce reports and make recommendations about how local health and care services could or should be improved;
- Have a seat on the local authority statutory Health & Wellbeing Board where they are an important contributor to the local work on reducing health inequalities;
- Help Healthwatch England carry out its role as national champion by telling it about the views and experiences of local people;
- Provide the information and advice function to signpost people to appropriate services. [Ends]