

ENHANCING THE QUALITY OF CONVERSATIONS WITH PEOPLE IN THEIR LAST YEAR OF LIFE

EARLY LEARNING FROM GREATER MANCHESTER



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1 INTRODUCTION

How do we create a better experience for people approaching or within their last year of life, based on person centred conversations, supporting people to live and die well?

This report describes and shares ideas and early learning from a project in Greater Manchester which explored person centred conversations for people approaching end of life, as a way of improving their experience, and that of their families.

The work was undertaken with Bolton, Trafford and Stockport, led by the Greater Manchester Health and Social Care Partnership and the Greater Manchester and Eastern Cheshire Strategic Clinical Networks – Palliative and End of Life Care Team. It was funded by NHS England’s Personalised Care group.

The work was initiated through:

- A clear interest from senior executives at the Greater Manchester Health and Social Care Partnership that end of life care should be a priority for an emerging programme on ‘person and community centred approaches’
- The planned development of Greater Manchester Commitments to Palliative Care Individuals Approaching or Within the Last Year of Life and supporting Framework that includes personalisation and care planning as an important component, building on national policy
- An opportunity from NHS England to draw down a small amount of funding to demonstrate personalised approaches for people at end of life.

“People are learning from each other. People are sharing not just practice but enthusiasm and drive and it just feels to me exciting to be in a context of so many people who believe so intensely that what they're doing is for the good of so many people.”

— Tony Bonser, North West Dying Matters Champion

2 BACKGROUND TO THE PROJECT

“Our ultimate goal, after all, is not a good death but a good life to the very end.” - Atul Gawande, Being Mortal: Medicine and What Matters in the End¹

How was the project developed and set up?

To explore and scope the work a series of workshops was held with a range of stakeholders across Greater Manchester to understand what had been tried and learned, and what the priorities and opportunities for further learning and progress in this area might be. A final workshop in May 2018 concluded that it would be helpful to develop, implement and further iterate a person-centred journey for someone from identification through to final days of life. This would be developed through drawing on best practice, and engagement with experts across Greater Manchester. It would build on the train the trainer skills and tools already being introduced as part of an existing programme and bring in other person-centred techniques and tools that have been shown to have benefits for people. It was agreed that three localities would lead this, and then the learning would be shared across Greater Manchester.

A process was set up to invite expressions of interest in being one of these localities, a panel including clinical expertise and lived experience expertise was convened, and three localities selected to receive funding plus external support to pursue their ambitions. The localities were selected in September 2018, projects were then initiated and delivered, with the final learning event scheduled for May 2019. This was a very tight timescale, driven by funding restrictions.

What was the rationale behind the project?

The emerging consensus, from the developing overarching Palliative and End of life Care Framework and the specific workshops was that in Greater Manchester, people want to have the best quality of life they can while they are living with advancing illness, and to have the most peaceful death they can, where they want to be, surrounded by those they choose.

The hypothesis for the project was that key to this is the courage and skill to have a good conversation with people about what is most important to them, and then to take action to deliver on this. All those working in Palliative and End of Life services believe in the importance of this, but often the realities of working in large complex systems can get in the way. The Innovation project for Palliative and End of Life Care was established to find out how we can deliver the most person-centred support possible so that all of Greater Manchester can learn how to make these aspirations a reality.

What did we hope to achieve?

Our aims were to:

- develop a practical but ambitious model that articulated what great person-centred care is for people from identification of people approaching or within the last year of life through to their final days
- ensure that the implementation was genuinely rooted in the reality of the people providing this support and the systems they work in
- provide a space for trying something new and in an environment where the project could evolve throughout according to the needs of those involved
- set a clear Greater Manchester expectation on the experience of care and what best practice is – to inform standards and metrics
- actually embed as practice in teams across Greater Manchester – starting in two localities and then being shared for all in 2019/20.

¹ Gawande, A (2014). *Being Mortal: Medicine and What Matters in the End*. USA: Metropolitan Books

3 WHAT THE PROJECT COVERED

Support and infrastructure

As part of the project, each locality was offered combined support from the Person and Community Centred Approaches team within the Greater Manchester Health and Social Care Partnership and the Palliative and End of Life Care Network within the Greater Manchester and Eastern Cheshire Strategic Clinical Networks.

A support infrastructure was put in place, to include:

- initial set up meetings to help clarify the aims of the project, the working relationship between the Greater Manchester team and the local leaders, plus to start to action plan
- the introduction of the project to the wider locality stakeholders by means of an information awareness raising half-day event
- a Memorandum of Understanding to agree respective roles and responsibilities and provide the basis for the funding to be transferred (see below)
- funding to free up capacity for this project including: dedicated clinical leadership; project support; backfill to enable practitioners to undertake training and coaching; communication and co-production costs
- direct relationship management, training support on person centred practices, and support to action plan – provided by in-house expertise from the Person and Community Centred Approaches team (Gill Bailey, Person Centred Planning Programme manager) alongside Elaine Parkin (Quality Improvement Programme Manager, Palliative and End of Life Care Team). This included a full-day train the trainer session on personalised care and support tools, a full-day co-delivery session and support with steering group meetings within the locality
- An additional offer of training support on Patient Activation Measures (PAM) from Dr Ollie Hart, which was activated in the later stages of the programme
- Three collaborative events bringing together all three localities to learn from each other, hear about and consider potential approaches and receive coaching and opportunities for planning support.



Supporting self-management

With the growing need to support people to self-manage and the associated requirement for health and social care systems to change how they deliver care and support, as part of the End of Life Innovation Programme, places were offered to each locality across Greater Manchester. Practitioners supporting people identified as being in the last year of life were invited to attend a two-day 'Patient Activation and Health Coaching' course delivered by Dr Ollie Hart from Peak Health Coaching.

Patient Activation is defined 'an individual's knowledge, skill, and confidence for managing their health and health care'². Using Health Coaching to tailor service delivery according to patient activation levels can maximise productivity and efficiency by ensuring that the level of support provided is appropriate to the needs of the individual.

Supporting staff to learn how to use these new approaches, whatever the situation the patient or person supported is at, is a fundamental part of delivering a sustainable and effective healthcare service.

Twenty-five people attended from across Greater Manchester and the evaluation found that participants took away new skills and were enthusiastic to embed the approach into their practice.

The training challenged and supported participants to think about patient activation for people within the last year of life and in particular in the area of approaching advance care planning conversations.

“End of life care can often become very medicalised. You know traditionally we've used lots of very pathway driven work and lots of attention to make sure we do the medical things, pain relief and making sure people don't have pressure sores and those sorts of things.”

“And often the person in the middle gets lost, and so it's so refreshing to see this sort of programme where you're focusing on those medical things as well but really tune into the personalised stuff, so it becomes an experience around what matters most to the person rather than just churning people through a medical pathway.”

— Dr Ollie Hart, GP

² Hibbard et al 2005

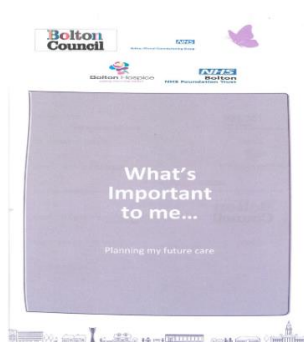
4 SPOTLIGHT ON THE LOCALITIES

Bolton

When they started on this project, Bolton had already radically improved the care they offer to people approaching the end of life through daily multi-disciplinary meetings hosted at Bolton Hospice. These meetings, which include the Hospice Liaison Nurse, Community Palliative Nurse Specialist, District Nurse Neighbourhood Representatives, Allied Health Professionals, Social Workers and the Community Consultant in Palliative Medicine had enabled them to better identify people in the community who might be approaching the end of their life and provide co-ordinated, and responsive support to them.



The team had already developed and started to use a 'What's Important to Me' document. Based on a document used in Salford, the document was shaped and developed by patients, carers and service users in Bolton, and covered a range of information that is important to an individual, including their likes and dislikes, the people involved in their life and how they would like their care to be delivered.



The team wanted to take this work to the next level through expanding the number of people who got to have a meaningful conversation about 'What's Important to Me' and really work through and crack the practical issues associated with providing person centred support to people.

The programme in Bolton had a number of initial aims:

- To recruit a dedicated administrator for the multi-disciplinary meetings. This provided the extra resource to improve the documentation and communication of discussions and outcomes around Advance Care Planning and Preferred Place of Care and Death
- To train and build confidence in frontline community staff in having person-centred conversations
- To embed the 'What's Important to Me' document and enable an understanding of the contents of those completed.

Following an introductory session and training events on personalised care approaches, it was evident that the work presented complemented the current patient-held 'What's important to me' document, which was being rolled out across Bolton, and this became a key focus of the project.

Staff were trained in person-centred approaches and 'What's important to me' documentation was provided to people. Alongside this, feedback was obtained, including an audit of the completed documents, the use of questionnaires on people's views of the documentation and some patient stories. Feedback was also obtained from staff on their views of the processes.



CASE STUDY

Claire, aged 57, is a lady approaching the end of her life.

Through the team having a person-centred conversation with Claire and filling out her 'What's Important to Me' document, they found out that what was really important to Claire was that she did not want her children to have to care for her in the later stages of her life. Originally from Merseyside, she also wanted to return there to be nearer to her extended family and friends.

The team was able to make contact with colleagues in Merseyside, to make the necessary arrangements for Claire to move back. Claire now has peace of mind, knowing that her children will not have to look after her and that she can be near her extended family.

In terms of embedding the 'What's Important to Me' document, the team at Bolton has used their daily liaison meetings, their care home project lead and education team to train staff in person-centred approaches to help inform their conversations with individuals, supported by the existing document.

- In the months prior to the project (June 2018) 3,000 'What's Important to Me' documents were printed and made available to community teams, the hospice, the hospital and GP practices. 'Person-centred' prompt



questions to the 'About Me' section of the document have now been added.

Person-centred approaches training has been delivered to 20 care homes (over 500 staff members), and over 100 staff have been trained in the hospice and externally. Three person-centred approaches sessions and two advanced care planning sessions have been delivered incorporating this training, with 'What's Important to Me' documents disseminated during the training. The team have also started to use one-page profiles in their child/teen bereavement sessions.

The team in Bolton now plans to continue the work started as part of the programme, and plans to:

- Embed person-centred conversations and documentation in Advance Care Planning training
- Continue the excellent work in nursing and care homes across the borough
- Further improving the person-centred documents
- Develop an approach to capturing the 'What's Important to Me' information in the Bolton Digital Care Record
- Produce some one-page and mini profiles for staff in the Bolton Hospice Day Therapy team and the In Patient Unit
- Add person-centred questions to the discharge summary.

CASE STUDY

Carol was able to provide information on what was important to her, not just about her preferred place of care or death:

"I want to spend as much time as possible with my family and cat. I want to wear my own clothes, have a vegetarian diet and if possible, I prefer a shower to a bath."

"The biggest thing that's come out of it is the relationships that we've built. The fact that we all know each other really well and how each of us works and there's no longer any them and us, we're trying to do the best for the patients that we're caring for."

- Dr Laura Edwards, Community Consultant in Palliative Medicine, Bolton

Stockport



Stockport has great support for the services looking after people approaching end of life.

Stockport NHS Foundation Trust initially applied to the Greater Manchester Health and Social Care Partnership to work with individuals living with advancing illness, to have their wishes core to their care and outcomes.

The aim was to develop and test a robust model for individuals in the last year of life in an intermediate care setting, however, the subsequent timing of the project was not ideal for the setting, so the decision was taken to use the work that had already been undertaken to link with a separate project.

The project 'Early Identification in Primary Care' is being delivered in conjunction with Viaduct Health in Stockport. The project is utilising a new electronic clinical search tool, the EARLY tool, to support early identification of patients within the last 12 months of life. The surgeries taking part in the project have access to a GP facilitator for support throughout the project.

The initial part of the project aimed to validate the EARLY tool within a clinical setting. The GP facilitator completed a retrospective audit of deaths over the last 12 months and ran the search tool on the active patient list at each surgery.

The information gathered allowed clinical validation of the tool and provided the practice with a list of patients who would benefit from supportive care planning.

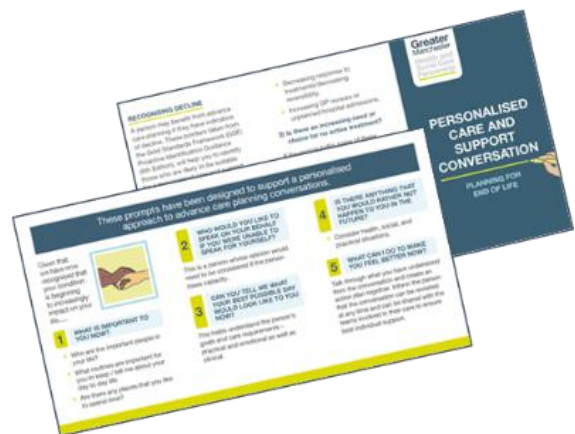
Once identified, the facilitator was then able to provide clinical support and facilitation of advance care planning discussions between patients and their usual care team. Written advance care plans were then able to be put in place to share this information with appropriate services.

Detailed conversations help find out what matters most to people, now and for when their death approaches, ensuring that services can help make these wishes happen.

In order to enhance the value of these advance care discussions, GPs and their colleagues in primary care receive individualised training, so they become confident and skilled in having personalised care planning conversations.

To support clinicians in developing these skills, a key card has been created in collaboration between the project team and Stockport clinicians.

This pocket-sized card helps clinicians to recognise signs of decline and then has five prompts which promote individualised conversations around advance care planning with these patients.



To date, the key card and training have been piloted in two practices in Stockport, with an aim to roll out to five further practices in the next two months. These seven practices serve a population of around 72,000 patients throughout Stockport.

Across the two practices the training was attended by the multidisciplinary team and included a range of individuals – GPs, practice nurses, a pharmacist and a Healthcare Assistant. A questionnaire was completed

at the beginning of the session to gain an understanding of baseline knowledge and skills.

Feedback from the baseline questionnaires completed showed that whilst most respondents felt comfortable with communication skills, there was a lack of knowledge and confidence about when and how to initiate personalised care discussions and advance care planning. This feedback supports a continuation of personalised advance care planning training at the five additional practices.

During the project the key card will be evaluated by the clinicians using it in everyday practice and feedback sought to refine the content. The questionnaire will be repeated for all clinicians who participated in the training and have been using the key cards to assess knowledge and skills at the end of the project timeline.

“With increasing multi-morbidity it can be difficult to recognise when a patient is entering the final phase of life. By this point it's often too late to have meaningful conversations about a person's wishes for living well right until the end. This project will be helping clinicians and patients to recognise decline earlier, ensuring time to have real conversations about what matters most to the individual.”

— Dr Charlotte Reddick, GP, Stockport



Trafford

Trafford Clinical Commissioning Group, together with St Ann's Hospice, wanted to work closely with care homes to introduce and embed best practice around person centred thinking and to use tools that support people to get the best possible care, including those living with dementia.

Both organisations wanted to support the care homes to work with people to think ahead and make plans for when they are approaching the end of their life, so that everyone works together to support them well in the present and help them to have a 'good death'.

The initial aims of the project were to:

- Identify and coach one champion in each care home
- Assist the care home to identify residents at the end of their life, using the North West End of Life Care model
- Facilitate the care home to embed this knowledge to set up a palliative care register in the home
- Re-establish Gold Standards Framework (GSF) meetings with GP involvement, by initially setting up and chairing the meetings
- Create the foundations of good practice regarding person focused end of life care in the home specifically focusing on advanced care planning and documents surrounding person centred thinking, such as communication charts and one-page profiles.
- Implement a rolling programme of training in the home including advance care planning, communication skills and the North West End of Life Care Model
- Liaise with external stakeholders, including commissioners to fund any specific needs and maintaining communication links with GPs.



However, the time constraints of the project and the demands on care home staff meant that the project had to focus on one key area. Working in three care homes (Faversham House, Brookfield Nursing Home and Allingham House), the team decided to focus as a key priority on the introduction of one-page profiles. This included:

- Working with staff, residents, families and key people to explain the approach
- Completing staff mini/one-page profiles
- Completing a specific number of residents' one-page profiles within the time of the project.

Over six months, each home received specific training, focusing on the importance of person-centred thinking at the end of life, producing one-page profiles and patient activation measures training. This was then reinforced by the Facilitator from St Ann's Hospice visiting each home on numerous visits to support the embedding of one-page profiles into practice.

The project relied on the courage of care home staff to alter their language and the culture of the home by having open and at times difficult conversations with residents and their families in order for a true and insightful one-page profile to be produced.

The results were better than initially anticipated, with the two homes that had previously completed the GSF programme, completing one-page profiles for all their residents by the end of the project and in the third home, although the profiles were not being produced, staff were more aware of the conversations that need to happen and understood their importance.

The work provided a number of benefits, including:


- Building up a good rapport with residents and relatives
- Positive experiences for residents and their families
- Better working relationships and continuity of staff
- Teamwork and good leadership

Staff were able to allocate time to the project and support each other to deliver excellent End of Life care.



“The work that has been delivered is wonderful and it’s building on the work that’s already been done in some of the care homes. I’d love to see this as standard across Trafford.”

— Commissioner, Trafford Clinical Commissioning Group

<p>What is important to me</p> <ul style="list-style-type: none"> • To see my husband and daughter. They come to see me often and I like to find out what they are doing. • I like to listen to music – the 60s is my favourite and I love to play my Beatles records. • I have a very sweet tooth and love any type of sweets and chocolate. Cadbury’s Dairy Milk is my favourite. • When the weather is nice, I like to spend time outside. I miss my garden so I love to be near plants and flowers. 	 <p>What people appreciate about me</p> <ul style="list-style-type: none"> • Caring • Thoughtful • Fun to be with • Always smiling 	<p>How to support me</p> <ul style="list-style-type: none"> • Make sure I have time outside in the garden whenever possible. If it’s too cold or wet, then put my chair near the window so I can see outside. • I get cold easily so please make sure I have a blanket to put over my legs. • If I have my earphones on listening to music, please come around and face me to talk to me as I don’t like surprises. • Keep my chocolate in the fridge – I don’t like it when it melts all over my hands.
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5 MEASURING IMPACT

“If you start to have conversations, you learn so much more. And if we don’t know what people want, we can’t help them achieve it.”

— Dr Laura Edwards, Community Consultant in Palliative Medicine, Bolton

The approach

Collecting data on the impact made on any initiative is important to help us to make better decisions about how to improve services, and to ensure that changes we make lead to positive change for people.

Given the relatively short nature of the project, it was recognised that there would not be enough time to assess whether there had been a significant impact across services, but it would be possible to assess impact for some individuals and that would enable to propose some measurements to take forward in the longer-term.

Discussions were held with each of the three localities to consider a range of measures that would be specific enough for their individual objectives, but also to be applicable for other programmes of work in end of life and palliative care.

Development of measures

The programme looked at a range of measures, with the aim of having a good mix of indicators, from measures of output and activity, through to outcome and impact. To supplement the data-based measures of impact, case studies and stories were also used to assess impact on an individual level.

The project looked at measures in three specific areas, covering impact on:

- The person, their carers and family
- The health and care system
- Activity or process

Locally suggested measures were cross-referenced with national requirements and were considered in light of what was already available, what could be collected without significant disruption and took in elements of activity and ‘counting’ to assess scale and coverage as well as outcome and impact. Discussions with the three localities led to a set of metrics covering three key areas:

- 1) Person centred plans and documentation
- 2) Appointments and treatment
- 3) Patient, carer and staff experience

In addition, a range of other more generic metrics were included in the suite. Finally, the set of metrics was reviewed to identify those metrics that were deemed to be ‘key’. The key metrics are shown overleaf. It was noted that whilst the project enabled metrics to be developed, full data collection was not possible in the timeframe available.

Alongside the measures identified, localities supplemented the data with case studies. Some examples of these are included within this report.



Key Measures

Person centred plans and documents

- People with Personalised Care and Support Plans
- Number of person centred conversations taking place
- One-page profiles completed (including who and what is important to the individual, what makes a good day etc)
- Audits based on features of the Person Centred Care and Support Plan

Appointments and treatments

- Length of stay in hospital (out of hospital care; patient care closer to home, or at home)
- Number of bed days in last 90 days of life
- Reduction in number of GP appointments
- Reduction in acute admissions (both elective and emergency)
- Number of A&E attendances

Patient, carer and staff experience

- Evaluation of IPOS-dem (Q6-8) and/or IPOS views on care to support person-centred end of life care
- Evaluation of case studies/stories - from perspectives of:
 - person
 - family
 - staff
- Achieving preferred place of death
- % of staff achieving signed-off training passport

6 TOP TIPS FOR THE FUTURE

“It is about understanding that what is important to us may not be important to the person we are caring for.”

— Training participant

The three localities learned a lot about the impact and benefits that a person-centred approach has for patients, families, carers and staff.

The process of taking part in a project such as this also provided a range of learning opportunities, that the teams will use in taking this work forward, but some of the learning is also applicable to a wide range of activities and settings. Some of the teams’ top tips and ‘lightbulb’ moments are:

Not doing everything we set out to do – doing less but well.

Evaluate each step and reinforce the goals.

Get the right people involved in the Project Group early on: agree roles/communication

Try not to carry the entire project on one person’s shoulders.

It’s all about the relationships!

We are slowly changing culture.

Set aside some time to develop the project, fully and engage staff and families.

Trying to spread the adoption of person-centred documents across the entire health economy is hard. But without this project it would be even harder.

7 SUMMARY

Across Greater Manchester there is a clear commitment to ensuring that people at the end of life should be supported to have the best quality of life they can while they are living with advancing illness, and to have the most peaceful death they can, where they want to be, surrounded by those they choose.

There is a recognition that having a good conversation with people about what is most important is at the heart of a good person-centred approach.

This project aimed to explore how this could best be done and be embedded so that it becomes a standard approach and something that everyone who finds themselves in this situation has access to.

We started with where people and systems were at. We built on excellent leadership and pre-existing work but were also very honest about what was happening that wasn't good enough for people and families, and needed to change. Through spending time and effort listening to people and families and what matters to them, we were able to find approaches that worked for them.

Some of the key things that we paid attention to were:

- Focusing on the individual
- Allowing time to have a good conversation
- Building one-page profiles and other documentation
- Providing staff through training and ongoing support with the skills and tools to be able to deliver a person-centred approach.

There were challenges along the way, and the project evolved as we went through, but the learning we gained is helping make changes to the way we do things and supporting people so that we can ensure that our aspirations will become reality.

8 ACKNOWLEDGEMENTS

We are indebted to all those people who worked on this programme:

- Dr Dave Waterman, Dr Liam Hosie, Kim Wrigley and Tony Bonser who helped with the selection of localities
- Dr Ollie Hart and colleagues at Peak Coaching and Training who provided training
- Staff across all organisations in the three localities:
 - Bolton – Bolton Clinical Commissioning Group, Bolton Council, Bolton Hospice, Bolton NHS Foundation Trust
 - Stockport – Stockport Metropolitan Borough Council, Stockport NHS Foundation Trust, Viaduct Health
 - Trafford – Trafford Clinical Commissioning Group, Trafford Council, St Ann’s Hospice, Allingham House Care Home, Brookfield Nursing Home and Faversham House Nursing Home
- NHS England’s Personalised Care Programme who provided funding and advice.

And a very special thank you is due to all those patients, residents, families, friends and carers who assisted us, provided such invaluable feedback and made this project possible.

The project was established and set up by the Greater Manchester Health and Social Care Partnership through a collaboration between the ‘Person and Community Centred Approaches’ programme and the Palliative and End of Life Network, which is part of the Greater Manchester and Eastern Cheshire Strategic Clinical Networks. Those leading it included Gill Bailey, Elaine Parkin, Zoë Porter and Ingrid Summersgill.



GET IN TOUCH

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