



Think Different, Think End of Life Care.



healthwatch Staffordshire

healthwatch Walsall

healthwatch Wolverhampton

Engaging Communities
Inspiring Change, Improving Outcome

acorns
Your local children's hospice

Compton Hospice
Caring Together

University Hospitals of North Midlands
NHS
NHS Trust

DougieMac
#morethanahospice

BJF
Beth Johnson

The Donna Louise
Children's Hospice

MRS Evidence Matters™

Alzheimer's Society
United Against Dementia

Background of project

After a public consultation, it was identified that End of Life Care (EoLC) was a priority for Healthwatch Staffordshire to focus their work on in 2017. Our local intelligence around EoLC suggested there were discrepancies in the way care was delivered across different parts of the County and the wider Midlands region. As a result, an End of Life Advisory Group was developed with local service providers from St Giles Hospice Care, Beth Johnson Foundation, Dougie Mac, Alzheimer's Society Staffordshire and Shropshire, Donna Louise Trust and University Hospitals of North Midlands (UHNM) led by Engaging Communities (ECS) and Healthwatch Staffordshire. The workstream that emanated from this group sought to identify barriers to a universal, holistic approach to EoLC with a focus on the areas of Staffordshire, Walsall and Wolverhampton. These findings were then considered against the national picture.

Three important task and finish groups were set up to undertake this work. These included Advance Care Planning (ACP), Workforce Development and Pre and Post Bereavement Support.



The main research question this project sought to answer through each of the task and finish groups was: **What are the barriers to a consistent, holistic approach to End of Life Care (EoLC) through multi-disciplinary collaboration?** The key findings from the groups can be found in this report. Detailed findings can be found on the Healthwatch website.

Methodology

The findings for the ACP workstream were found through a round-table discussion with EOL professionals and 3 focus groups conducted at a hospice. The Pre and Post bereavement support workstream used a mixture of focus groups and interviews with EOL staff and service users across 4 hospices to gather the findings while the workforce development workstream used questionnaires completed by EOL education leads and trainers from hospices as well as a literature review of existing research. All of the results were then analysed to identify common themes.



Advance Care Planning (ACP) Findings

Commissioning Barriers

Lack of joined up systems: Lack of integration of IT systems may mean that information about an Advance Care Plan may not be communicated to other professionals and could lead to duplication of work.

Bureaucracy of ACP: The expectation that advance care plans must be completed is said to turn it into a meaningless, bureaucratic exercise for staff.

“I think it feels like it’s a requirement to go back to meet targets, rather than the patient’s need or wishes.”

Provider/Staff barriers

Documentation problems: There are a range of different documents being used which complicates the system and duplicates the work.

“It gets split up, doesn’t it? There’s some conversations in the notes. There’s some conversations go in the booklet. Some information ends up on the discharge letter, some on the discharge summary letter.”

Lack of follow up of ACP: ACP is not always followed up, and therefore, any changes in preferences or updates are not followed through the chain so every healthcare professional working with patients is aware of their preferences and wishes.

Lack of confidence: Even though staff have been provided with training, not all staff feel confident enough to have conversations about ACP.

“There’ll always be a bit of dread when you take out the advance care plan, that even though you know you’ve had the conversations I’ll always have that dread... I will never feel completely competent.”

Practicalities of preferences: It is not always possible for staff to fulfill patient requests, due to the lack of resources, bed spaces, finances etc.

Lack of experience among staff: Some staff members, especially new staff members, have not had the experience of doing ACP and therefore are more afraid to approach it.



"[My patient], he changed his mind weekly sometimes, he wanted the zoo and everything... We couldn't achieve it. We were going to have animals come in here"

Time consuming process: ACP requires more time than perhaps a busy health professional can offer, in a normal working day.

"I think because it can be quite time consuming...[it is a] barrier to actually doing it and encouraging it to work."

Public barriers

Lack of awareness: Many individuals have no idea what ACP is, and therefore, have never thought about having one.

"I never had any personal experience before being in the present role until I was taught...it's a shame that it isn't more out there, and it's up to us to actually provoke that conversation, and it should be anybody provoking that conversation."

Fear of talking about death: The discomfort of speaking about death makes it difficult to approach subjects like ACP.

"50 years ago you would have a nuclear family where death was very common, the person would be at home, die at home, the wake would be at home, they would go to the funeral from home; it was very open. We hide it now. And that's the problem."

Lack of interest: ACP is not something everyone will engage with and therefore, it is difficult to involve people in the process.

"I think it's not for everyone, and I think it's important that we don't sort of try and push it on people...We can sort of start to open that discussion, but if they don't want to discuss it, then I don't think we should...I find that I'm okay with that."





Pre and Post Bereavement Support Findings

Overall, service users who have used pre and post bereavement services have found them to be valuable, whether that be 1:1 counselling, group support, online support, or another form. Several participants reported that they wanted to be given some time before accessing the available support, and appreciated being able to get support when they felt ready. However, some participants did identify some barriers.

Service User barriers

Insufficient individualised

support: Some participants reported that the support that they received was not individualised and did not take into account the personal wants and needs.

“in terms of the post bereavement support I don’t think there has really been very much, most of the bereavement support that I’ve had over the past 15 months is what I’ve sought myself, in the form of online forums and Facebook groups...I think in terms of what was actually made available to us at the time through the hospital, it wasn’t very much.”

“I do think it (counselling) should be more accessible but how or what I don’t know.”

Support came too late: Generally, if a next-of-kin has had a family member who died in the hospice (or under the

care of hospice staff), offers to take up bereavement support was provided approximately 6 weeks later. Despite the fact that most participants felt that the support was offered at the appropriate time, some still felt that it was too long a wait.

“It’s when you need the help earlier on you don’t get it. And they were great, I mean when [the hospice] kicked in all the help came. But then it was too late.”

Support needs to come to them:

At the point in their lives when things are complicated and difficult, participants feel that giving them information about where to go is not enough, but rather for the services to come to them instead.

“If you’re at the point where this sort of pre-bereavement situation is arising, the person that you’re caring for like we are, our brains are so wrapped up with caring for the person, wife, husband, whatever, that the idea of trying to, or even having the time to try and go out and find somewhere we can have this pre-bereavement counselling or be supported is something we can’t do. We’re wrapped up. Unfortunately it’s a situation where it’s one way traffic, it’s got to come to us and that is something I found was not there.”



Lack of awareness of support outside hospice:

The bereavement support is only known to next-of-kin due to their connection to the hospices. Therefore, only people who have accessed the hospice for a dying relative have any awareness of bereavement support. This is not always the case for people who have had family members who died outside the care of a hospice.

“Friends don’t get any support because they are not associated with [the hospice]. They have no idea about what is out there.”

“Partners may die at home and therefore not reached out to. I felt fortunate that it was offered to me but had he died at home it may not have been offered (may not have known about it).”

pre-bereavement work around the patient’s wishes.

“The difficulty is if we have hospice discharge referrals quite late and they are dying when we first go in, you haven’t got time to fully explore advanced care planning, and that can be very difficult...But it’s very difficult if it’s a Friday and you get a phone call to say this persons’ been fast tracked home somebody needs to go and see them and they’ve died the next day that’s very difficult..”

Difficult to access: Staff in hospices have acknowledged that they are not able to work with people who are either not a patient or had friends or family involved with the hospice. They also acknowledge the difficulties faced by people wanting to access services in the community.


“When trying to signpost families who are needing additional support at a level that we are unable to provide, we do run into some difficulties.”

Staff barriers

While staff felt that the services they provided in hospices was good, external factors and resources make it difficult for pre and post bereavement to become consistent.

Late Referrals: Staff found late referrals very difficult to deal with. Earlier referrals enabled them to get to know patients and families and begin





“We’ve had a number of people phone in to ask for our bereavement support but we’re not able to provide it and it does take quite a considerable amount of time for people to get bereavement support. There’s quite long waiting times.”

Social barriers

There is a taboo around discussing death and dying as well as dealing with grief.

“I think the main barriers will be people’s views on bereavement support, because a lot of people very much just don’t discuss it.”

“A fear. I think people are afraid. I’m sure we’re all afraid of dying, I’m sure that’s an instinctive fear, and yes we’d all like to think when it’s our time we could sit in a chair with a cup of tea and feel a bit tired and close your eyes and go to sleep. That’d be wonderful. 99.9% though it’s not going to.”

Resource and financial barriers

Bereavement support services are very resource and finance reliant, and take time and money to work effectively.

“I think probably the other elephant in the room here really is that all of these services, and I’m not just talking children’s hospices, but bereavement

services in general are very resource and finance reliant.”

“Money, time... everywhere has its own different issues, different social and economic circumstances which makes a big difference to the families who are being dealt with.”

Disagreement around definitions:

National documents are confusing as to when an EOL pathway is triggered. Therefore, the public are unsure of the right time to seek support.

“All the national documents are very conflicted, end of life in some of them is the last weeks, the last days, the last years, so there’s no national agreement on what it is”

Professionalisation of

counsellors: Counselling services generally are reliant on volunteer counsellors. These individuals are trained professionals (most with postgraduate qualifications) but are not valued for their work as their undermined by the lack of paid jobs in the sector.

“Is this the norm across all bereavement services? Services are reliant on volunteers. Professionalism and value of service and those who work for the service are undermined by lack of paid jobs”





Workforce Development Findings

Workforce retention and recruitment

There are currently major issues across the country relating to staff retention and recruitment which has a direct impact on the ability to provide and sustain EoLC training. The specialist palliative workforce is low and health professionals with expert knowledge in palliative services are limited (1). With much of the older staff members approaching retirement, the lack of staff make it difficult to not only release other staff members for training but also to retain highly skilled professionals.

Cost of training: The cost of training staff members is currently too high to meet due to the reduction of funding across health sectors. The reduction in funding pots across the county mean that health services have less money to put towards training needs.

Staff workload: Staff workloads can also mean that they do not have the time to commit to training needs. This commonly results in cancellations or dropouts for training in order to prioritise service delivery (2).

Ability to release staff from their workplace to attend training:

Despite the fact that there is study leave permitted for staff to take each year, staff shortages and high workloads make it difficult for services to release their staff to take on training.



1 Census of consultant physicians and medical registrars in the UK 2012. The Royal College of Physicians.2014

2 The Democratic Society. (2015). Training and education in End of Life Care. Recommendations for Health Education England.

Key recommendations

1. Bring ACP out of EoL and into public domain.

We have car insurances for the possibility of an accident, why wouldn't we be prepared for our future health preferences? More awareness needs to be raised as there is no need to wait until a terminal diagnosis to have an ACP (Advance Directive, Living Will or Advance Statement) put in place. This process could be incorporated into various life milestones such as buying a house, getting married or having children.

2. Recognition of skills and value of bereavement service.

Participants felt that the role of bereavement counsellors should be recognised for the skill and professionalism that it requires. Because the majority of services rely heavily on volunteers rather than providing paid roles, this can undermine the value placed on the service by users. Measures to address this could be diverting funding to the VCS sector to this support cost-effectively; giving greater recognition and value to the role; asking families to make a voluntary contribution; using a prescription style approach with low income families accessing without charge whilst those that can afford it pay. More awareness of services should also be raised with GPs and other NHS services for them to refer patients to.

3. Being able to release workforce to attend training.

There should be a push to provide training for every GP on ACP which would save money down the line by preventing wastage in how people are cared for towards the end of their lives. Other options will be to use locums, use a more effective rota system, use of volunteers for non-medical activities, as well as recognition and added value for staff who do training outside of work hours are possible methods that may be able to achieve this outcome.

4. Utilising shared online systems

to develop a patient portal which can be accessed by all professionals involved in the patient's care. These shared online systems should be able to work across healthcare services, providing relevant information to all the services the patient uses (e.g. NHS, hospices, Third sector support services). Password protection and encryption can be embedded to ensure that only the relevant information in shared across services and that confidential information can remain private and within the individual servers. This should be looked at as part of the STP work on Digital Roadmaps..





ENGAGING COMMUNITIES

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As a partner of the Market Research Society, we maintain the highest standard and offer a professional, independent service.

Our expertise in consulting on sensitive issues combined with a successful track record of researching socially excluded groups also means you gain evidence and insight across the whole spectrum of your services and user groups, including those who are traditionally more difficult to reach

Our Techniques:

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- Consultation analysis
- Secondary data collection
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5. Bespoke Research Project		1	2	Multiple
6. Social Media Dashboard			☺	☺
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