Norfolk Older People’s Strategic Partnership (NOPSP) meeting minutes

Thursday 28th September 2023 at the Diamond Centre, Norwich, NR7 8TR

Attendees

Ann Donkin	Age UK Norfolk
Sue Moore	Deaf Connexions
Guy Peryer	University of East Anglia (UEA)- Speaker
Audrey Harnden	Broadland Older People's Partnership (BOPP)
Anneliese Maerz	Age Concern North Norfolk
Sharon Wrath	Norfolk and Norwich University Hospital (NNUH)
Derek Land	Public
Catherine Van Battum	North Norfolk District Council- Speaker
Lauren Pashley	Home Instead
Linda Tuffield	Public
Tony Powell	Broadland Older People's Partnership (BOPP)
Malcolm Court	South Norfolk Older People's Forum
Julie Helsby	South Norfolk Older People's Forum
Caroline Barry	Norfolk and Norwich University Hospital (NNUH)- Speaker
Mary Ledgard	Norfolk Older People's Strategic Partnership (NOPSP)
Janine Hagon-Powley	Norfolk Older People's Strategic Partnership (NOPSP)
David Button	Norfolk Older People's Strategic Partnership (NOPSP)
Kaitlin Ferguson	Creative Arts East
Michael Chenery of Horsbrugh	Adult Social Care Committee Older People’s Champion
Ann Pulford	Public
Anna Sutton	Public
Debra Lawrence-Bell	Norfolk County Council
Rik Martin	Community Action Norfolk (CAN)
Judith Berry	Careline
Betsy Stainsby	Careline
Tasha Higgins	CAN- Minute taker

Apologies

Alastair Roy	Age UK
Niki Park	Norfolk County Council (NCC)
Erica Betts	NNUH Governor
Sue Whitaker	Age UK Trustee
Caroline Varney-Bowers	NCC
Sharon Brooks	Carers Voice
Aliona Derrett	Hear for Norfolk

1. Welcome and Introduction

[1]Mary Ledgard welcomed everyone.

2. Speaker: Dr Guy Peryer regarding https://compassionate-communitiesuk.com/

[1] The following points were made by Guy, who shared a Compassionate Communities Charter:

- A Public Health approach to palliative and end-of-life care aims for prevention or harm reduction, and person-centred care in the provision of health care. The unit of care is broader than the person, it includes family and those people important to you. There is a network of interconnected people who are influenced by a death, its build-up and aftermath.
- Compassionate Communities needs to be considered in a health promotion context. One description of health is the capacity to cope with the human reality of death, pain, and sickness i.e., health is about resilience and being robust against certain adversity. The image of death is the culturally conditioned anticipation of an uncertain date. This anticipation determines a series of behavioural norms during life and the structure of certain institutions. We don't talk about death and dying because for a lot of people it is distressing to think about, so we avoid it until it happens, but we do need to talk about it. What is the value of exposing ourselves to the realities of this situation and mitigating some of the potential trauma that could occur?

- There are expanding demands on end-of-life care services and a high turnover. Over the next 15 years more people are expected to die each year. Currently most people are dying in hospital, creating service and flow issues. Increasingly complex systems to navigate, with systems not talking to each other. Technology is great until it's not and everyone can be frustrated with it e.g., no longer possible to speak to someone have to go through websites and apps.
- Part of Compassionate Communities is about putting some humanity back into some of these more procedural elements with collective action and cooperation. Compassionate Communities influences all the aims in the NHS’s Long-Term Plan, especially people's experience.
- Those living at home with a life limiting illness may come into contact with services for up to 5% of a day, leaving 95% of the day where they are in contact with family etc, or the person is fending for themselves - what are we doing to occupy that time? Culturally don't want to burden, be a bother, but the consequence of avoidance is a high likelihood of harm. Dying is associated with a medical process, not a medical event with a social component yet so much of the experience is non-medical e.g., no longer being able to walk your dog.
- The person and their family are in the centre, surrounded by their inner network of close friends and alpha network of community groups, neighbours, associations. Further out you have service providers who are quite far removed in dictating what individuals can and can't do.
- There are six ambitions to try and improve the context of palliative and end-of-life care in this country, with compassionate communities particularly reflected in ambition six - each community is prepared to help. What does the community need to feel prepared in terms of education and capacity? We need to be asking what help people need (while respecting their wishes)?
- Traditionally struggled to get people involved in palliative and end-of-life care because of the social dilemma. Individually its advantageous not to think about dying but collectively it would be great if everybody had an advance care plan, if everybody's family knew exactly what their wishes were and it was all planned out - collective benefit.
- The state of nothingness after death is identical to the state of nothingness one was before birth. There is no such thing as a dying person, you are either dead

or alive. Our opinion of dying and death and fear dictates so much of our behaviour. If it's causing anxiety, explore what exactly is causing our anxiety - Cognitive Behavioural Therapy (CBT). Identifying what is essential in your life brings you more focus, as there is a correlation between anxiety and a sense of a life unlived. What is essential for you to feel like you have lived a good life? In the context of Compassionate Communities and neighbourhoods, enabling people to experience what they see as a completed life within the context of their living. Looking back on our experiences at their peak intensity, we often label them good or bad and crucially how they end. How can we facilitate better endings for people and their families?

- Health care usage in the last year of life goes up, with a massive spike in the last month as reach a state of uncertainty and often no alternative than calling 999 - what are the alternatives bearing in mind some of the inevitability and people’s wishes?
- We don’t have death literacy (experiential, factual, practical and community knowledge) unlike health literacy (right foods to eat etc) and public health interventions for harm reduction (e.g., seatbelts).
- Community asset mapping pilot in Halesworth (framed as a treasure map) asked people to walk their streets, writing down what they observed in terms of what may reduce the intensity and stress for families in a palliative and end-of-life care context e.g., pubs and cafes offering a listening ear or dementia friendly trained staff, pet shops offering dog walking or food delivery, a photocopy shop helping with legacy and memory boxes. We need to be more aware of being on each other's radar - interconnections. An informed community is an empowered community - social participation in health care. Need to use technology to our advantage as much as possible, thinking about usability, inclusion, empowering people to inform ‘directories’. What's important to people? How do they want to be known?
- “You don't know what you need to know until it's happened, by which time you're exhausted and stressed out. We didn't know what questions to ask, and if you didn't ask the questions, you didn't get the answers.” Part of the Compassionate Communities Charter is working with schools, colleges, workplaces, and

employers. There are milestones in life where we know what's coming, but still avoid talking about it or planning ahead, yet we want to consider people's wishes.

- Hospice UK Planning Ahead https://www.hospiceuk.org/information-and-support/your-guide-hospice-and-end-life-care/planning-ahead (includes information on advance care planning). When it comes to end-of-life we commonly prioritise quality relationships with happiness and fulfilment, achieving meaningful goals and purpose (identifying what's essential), gratitude, positivity and giving back. How can Compassionate Communities enable these? Ask people and ask them again because over time wishes, goals etc change. The best way to approach fear is exposure and togetherness, and the heart of a Compassionate Community is sharing this burden. Often, we are expecting resource to come but nothing is going to happen unless we do it.

[2]Attendee Comments:

- The Salvation Army previously created a ‘Dying Well’ resource pack of important aspects, including bucket lists, writing a will, funeral and probate plans, power of attorney, writing of funeral/cremation service. Those grieving won’t necessarily know or be able to deal with decisions such as selecting music the person liked.
- Some older people don’t have good family support or many friends (as they have passed away), or unwell and can’t get out of the house. Those with family can be impacted by family breakdowns and/or families wanting to take control in a direction the person doesn’t want to go (can’t do what they want e.g. shouldn’t be driving any more, live with us). A lot of people don’t have a kind, compassionate family who are willing to listen where person feels they can say what they want and how they feel.
- In the absence of family, the ambition is that other members of the community feel equipped and have capacity to step in - we still expect everything to come from the private sector. The trajectory/norm for most people, in the absence of a harm reduction approach, is a heavily medicalised death (999, A&E, hospital) that isn’t always beneficial, only by non-medical interventions can we reduce the inherent harm. About a quarter of a million bed days in the last 90 days of life are spent in a hospital bed - a significant amount of resource going into expensive acute episodic care. How can we get away from this overmedicalisation?

- The importance of and need for people to be able to speak to a person when ‘defeated’ by digital to support them in discussing/doing advance care planning etc, as many don’t know how even though information is available online. How do we make the digital world more positive and not thrust upon people to save costs - Conversation partners that enable informal and functional conversations in homes.
- If Compassionate Communities is costing too much, we are doing it wrong, some aspects shouldn't take money as talking about neighbourliness and preparedness, even volunteering is too formal, but it is a culture shift. How are we informing our community and enabling access to information - you need the platforms to share information, as well as places and spaces for people to convene.
- A ‘Life's Questions’ project in Suffolk went into primary schools to talk about loss - if friend in your class was going through this, what would you do? Is it right to ask how they're doing?
- If you are working class and want to support your community but got a busy life, finding time during the day is really tricky - not conducive to civil society. UEA is trying to establish a Civic University.
- There's plenty of support out there but you have to be pretty savvy to find it, and many people can't do that especially those living in isolated areas with no relatives or friends to help them. No central contact to point you in the right direction.
- We need to acknowledge that there are many medical points of contact and to identify opportunities for exploring social relationships and other support provision within these.
- There isn’t always the infrastructure to do a digital approach well. It's important to raise awareness that you can be digitally excluded because of where you live or the complexity of unfamiliar processes e.g., car parking payment by app only.
- We have Social Prescribers and Community Connectors in GP surgeries that can support but other health professionals are sometimes not aware of or utilising them, with social questions not being asked.

- Each district has resilience plans for all its parishes outlining who in the community can support in event of a flood, fire etc, although these could be improved, they could link into Compassionate Communities.

3. Speaker: Dr Caroline Barry (Palliative Care Consultant) on End-of-Life Care

[1] The following points were made by Caroline:

- In 2020 became NNUH Service Director (Palliative Medicine) overseeing the integration of medical teams across NNUH, Priscilla Bacon Lodge and community palliative care services in Norfolk. In April 2023 appointed Speciality Palliative Care Adviser to the Integrated Care Board, which is currently going through a restructure with jobs at risk and redundancies. We can't wait until we've got money because there isn't any.
- CPR (Cardiopulmonary Resuscitation) is the medical intervention when someone's heart stops to get it working again, either using a defibrillator or by pumping the chest. Its effectiveness is overstated amongst the public. In hospital the chances of recovering after cardiac arrest are 10 to 15%, in a care home about 3% and if you have lots of medical conditions (frail) about 1.8%. Yet it's a medical intervention that most people end their life having, sometimes when a ‘Do Not Resuscitate’ (DNR) is in place as it can’t be produced in the moment to override medical instinct. There are a lot of things in favour of embarking on CPR, even though we know it's not particularly effective.
- A conversation should be had in advance of a cardiac arrest, taking everything into account, to decide on balance whether giving CPR is going to make things better - may want a natural death, can't reverse the cause of a cardiac arrest etc. Only medical procedure where you must get consent from a patient not to give them a treatment - how this is talked about is the root of a lot of problems. There is a duty to consult/have a conversation with patients and family members about a DNR, but not to sign anything or say I don’t want to be resuscitated. The function of the DNR is a recommendation by health care professionals that it won't be an effective treatment in the event of a cardiac arrest, and our duty is to inform families that we've made that recommendation. What we need to say is this is not a successful treatment for you. Trying to have that conversation when

there isn’t even a curtain between two patients is challenging and so best to have that conversation in a planned way with trusted person.

- It can also be difficult if patients do not have the capacity to participate in this conversation - drowsy, delirious, confused, isolated, vulnerable, life-threatening condition. You can only consent to a treatment if you have the mental capacity to participate in the decision-making process, which might be obvious or require a capacity assessment. If someone does not have mental capacity, then a best interest decision/recommendation is made.
- In my opinion, the DNR CPR process is no longer fit for purpose, the ‘red form’ can be a stop sign for receiving CPR, intravenous antibiotics or access to critical/intensive care and admission to hospital. It was never intended to convey those messages.
- ReSPECT (Recommended Summary Plan for Emergency Care and Treatment - neutral process) enables people to document their wishes and preferences (rating on a sliding scale, whether on balance, prefer to prioritise quality or quantity), with contextualised recommendations on whether to give CPR (a small part). Majority of the form is about understanding the likely trajectory of a person's illness and what matters most to them, in terms of medical treatment and wider societal functioning.
- We don't think of a shopping list of treatments we may or may not want, more likely to conceptualise treatment in terms of where being cared for, whether person looking after us at home is being well supported, whether the outcome is likely to restore us to a worthwhile quality of life rather than a prolonged life.
- A completed ReSPECT form only comes into being when people can't speak for themselves about what they want and in an emergency situation. In Covid, decisions about whether appropriate to give intensive care e.g., ventilation, a lot more pertinent than CPR with ReSPECT fitting perfectly into pandemic planning as the DNR form wouldn't have been able to reflect any of that decision making. However, introduced in an entirely different context to the one originally envisaged, which was more of a public health approach, so has become more of a medicalised process and form and does not have the quality it was supposed to encapsulate. The ReSPECT form is the product, but the concept is the ReSPECT process - asking how people are and their understanding of their

situation, what their treatment goals are or what health care outcomes are important to them, introducing themselves and making a medical plan that's reflective of the reality of their medical condition and their goals, all of which should be part of basic interactions in a health care setting. The quality of conversations that take place is poor and the level of understanding taken away from them is also very poor.

- Trained a cohort of people in competently having the ReSPECT conversation and making decisions without having to bring in doctors, as recognise doctors aren't necessarily the right people to have that conversation.

[2]Attendee Comments:

- ReSPECT could be communicated better to people in hospital. Often people only want resuscitation if they can get back to the state they were before, which may not be simply yes or no but CPR for a period of time until the balance has tipped. **Caroline:** Tell your loved ones what your ‘red’ lines are and have formal mechanisms in place, such as power of attorney, in advance.
- Differences of opinion amongst clinical staff on whether to resuscitate or not, can lead to different outcomes. Mismatch between individuals not wanting to be resuscitated and medical instinct.
- Some people may decide to die in hospital because they don’t want to see family and friends in distress or be a burden at home, even though they might prefer to die at home. It is possible to have a good death in hospital, about whether it fits with persons wishes at that point in time. Not everybody's home, family or social network has the resource (physical, psychological and/or financial) to facilitate/support dying at home. Average of 90 carer hours a week to care for a person with motor neurone disease at home.
- There needs to be a campaign aimed at public and health care professionals about this very specific intervention. 50% of people in hospital right now will die within a year yet we almost pretend they aren't likely to die.
- DNR’s signed many years ago are still valid, but they are not legally binding documents rather an instruction to health care teams on an agreed plan. Ask your GP if your records are up to date and whether it would be helpful to complete ReSPECT. Hospital isn't the right place for that conversation, it needs

to happen beforehand. Having this planned and relevant health paperwork easily accessible at home also enables you to show this information to ambulance etc facilitating treatment at home.

- Where is ReSPECT held and how accessible is it to different medical staff?
- Lions Message in a Bottle https://lionsclubs.co/MemberArea/home/lions-message-in-a-bottle/ for people to keep important personal and/or medical details where they can be found in an emergency (or where in the house these are). The little green bottle is stored in the fridge and two stickers are provided: one for the fridge door and the other for the inside of the front door. FREE of charge to members of the public.

4. Speaker: Catherine Van Battum, Health and Communities Team Leader at North Norfolk District Council on PositiviTea Sessions (started in May 2023)

[1] The following points were made in addition to the PowerPoint shared:

- The team is out in the community (libraries, foodbanks, wellbeing walks, bereavement cafes, toddler groups) and all sorts of community events building connections. Our weekly themed radio show, from veteran to bereavement and dementia support, has built up a library of about 30 shows.
- With PositiviTea we wanted to create a really welcoming, inclusive environment for face-to-face conversations with free tea, coffee, cake, activities such as conversation Jenga, and lots of stalls and information from different organisations (statutory and VCSE) to get people talking. Locations have included Cromer, Fakenham, Wells, North Walsham, Sheringham, Holt, Mundesley, Stalham with specific local community groups and support who often don’t know each other exist.
- Hope to run this every spring and autumn but dependent on us being funded further, as currently only funded until early spring.

[2]Attendee Comments:

- How do we get this sort of initiative in other areas and through other Health and Wellbeing Partnerships? Given that NOPSP should be looking at ways of talking to older people it is something that could be explored within our older people’s forums e.g., one event a year in South Norfolk. Careline expressed an interest as they give free talks about their services.

- Suggested that a proposal is shared with Parish/Town Councils and other organisations/services that looks at community asset options e.g., community centres or local libraries, asking whether they would like to put on an event as always looking for ways to improve their community offer. Bring in and collaborate with other partners that draws in people, such as Wellness on Wheels or Cuppa Care Bus.

5. **Mary Ledgard, Interim Chair of NOPSP on 'Living Longer, Living Well'**

Attendee Comments:

- There is a lack of understanding about technology to make landline calls changing from analogue to digital (see Age UK article https://www.ageuk.org.uk/information-advice/money-legal/consumer-issues/changes-to-landline-telephones/) which your provider will contact you about doing if relevant, and the need for clearer information to avoid anxiety. Careline leaflet to be shared via email.
- The value of parish magazines, GP surgeries rolling screen, libraries and other public settings with footfall for sharing information/leaflets/signposting as people don't always have the confidence to speak to people. Every service has a single point of access, creating multiple single points of access when you are trying to access services.
- NOPSP are contacting churches and different faith centres to share Your Voice in Norfolk newsletter so they can take relevant extracts to inform their community.
- A point of contact e.g., Community Connectors in Districts, are key to helping people navigate their way to the information they need, because sometimes you don't know what you need - generic point of contact who knows where all services and resources are and how to navigate through the plethora of information and services is useful. No shortage of resources, skill and commitment in Norfolk to help people in later life. It's just all over the place and people don't know how to tap into it.
- Adult Social Services, when permission/consent is given by those they are supporting, can now access part of clients GP records (shared record), enabling social workers to see what has already been put in place, have more

knowledge/full picture of the person they are supporting. The individual has total autonomy on who we share information with and what information is shared e.g., asked for consent every step of the way such as referrals. Further literature will be shared. A lot of people are not that confident about enabling access.

- A key safe can enable emergency services, such as ambulance, to gain access to your home without having to knock down your door which then needs to be boarded up, restricting discharge and access for a period of time as a new door needs to be claimed on home insurance or funded. In Norfolk there is a campaign to raise awareness of the value of installing a key safe and registering any existing or new ones with the East of England Ambulance Service, who will only share this with an ambulance crew during an emergency. They can be placed anywhere on your home, and you have total autonomy on who you share the code with, and the code can be changed by yourself at any time (you will need to inform relevant people of the new code). Much safer than giving out keys and having to change locks. In West Norfolk, anyone over the age of 65 would be eligible for a free installation of a key safe.