**South Locality Meeting Minutes – Online on Zoom**

**Monday 25th October 2021**

**Introductions and apologies:**

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| **Attendees:** |
| Malcolm Court | Carer, Member of Carers Voice, South Norfolk Older People’s Forum  |
| Joy Welford | Carer, Carers Ambassador  |
| Tracey Sismey  | Chair, Family Voice Norfolk |
| Clare Randall | Family Voice Representative  |
| Sophie Little | Membership and Grants Officer, Carers Voice |
| Catherine Kennedy | Carers Voice Co Production and Facilitator |
| Stacey Robertson | Family Carer Practitioner in South and Breckland, Carers Matter Norfolk |
| Rosie Bloomfield  | Community Development Worker for South, Healthwatch Norfolk  |
| Kristen Hall  | Communications and Engagement Lead- Programmes, Norfolk Clinical Commissioning Group |
| Jill Curtis | Carers Lead, Norfolk and Suffolk Foundation Trust |
| **Apologies:** | Sharon Brooks, Kate Draycott |

**Minutes, Decisions and Action Outcomes**

The Patient Experience Team at the Norfolk and Norfolk and Norwich Hospital (NNUH) have spoken to ERS and have planned for them to attend Carer Awareness training.

Tracey asked about visitors at NNUH and queried the following hospital policy: *The family (unpaid) carer will be asked to leave the bedside during the dedicated visitor’s time with the patient.’* Are Carers only required to leave if they have other visitors during the vising hours?

**Action:** Catherine to find out the updated information about the NNUH hospital policy.

Alex Stapleton is now the contact person for the digital inclusion project.

Uptake on previous training with Carers Matter Norfolk has been low so other options are currently being looked at.

Discharge to Assess. Carers have been liaising with the discharge to assess teams. Carers have been working with the Discharge Improvement Clinical Lead at the Norfolk and Norwich University Hospital to develop a next of kin/Carers/significant other card for discharge.

Wellbeing packs have come to an end online but there are a few places that have packs available.

The Grants Panel are meeting on 26th October 2021 to discuss applications that have been received.

Kerrie Campbell has now left Carers Matter Norfolk. Michelle Wilkins is the Community Engagement Officer.

**What Matters to Me:**

A Carer shared their experience of a recent stay at the Norfolk and Norwich University Hospital. They mentioned that they are a Carer, but no other questions were asked of them. This is very disappointing. Nurses do not have the authority to look at database to see if the patient has an emergency plan. They have to feed up to their manager who initiates the emergency plan. Questions asked about how well Carer support is working on the ground.

**Action:** Catherine to raise experience with PALS and Patient Experience Team.

The Norfolk County Council emergency card was discussed. More information about this can be found at <https://www.norfolk.gov.uk/care-support-and-health/get-help-with-looking-after-someone/support-for-carers/sign-up-for-a-carers-emergency-card#:~:text=An%20emergency%20plan%20is%20a,unable%20to%20in%20an%20emergency.&text=Carers%20are%20now%20able%20to,plans%20with%20Norfolk%20County%20Council>.

It was felt that informing a member of staff at the hospital that they are a Carer should be enough to initiate a conversation without having to mention the Emergency Plan and Carer’s card. Another experience was shared about when an emergency plan had been initiated after a Carer had an emergency. Even though the Carer was unwell, they still had to arrange care. Questions asked about who is responsible for this if the Carer is too unwell?

Finances were discussed and purchases to support the cared for too. There are costs associated with all activities especially if someone isn’t working. Disability Related Expenditure and Minimum Income Guarantee say that people have enough money to live on but this does not take into account all costs. These costs include things such as lunch for personal assistants and travel costs for Carers plus the people they are caring for to get to appointments. These issues have also been raised at the Norfolk County Council Reference Group meetings.

Juggling work and caring at the same time is extremely difficult. A Carer explained that they recently created a list of expenditure related to the person they are caring for including a mobility scooter and handrail. They have submitted this list to Norfolk County Council in reference to their financial assessment along with receipts. People don’t fully understand the financial costs that Carers take on.

Norfolk County Council can support people with budgeting.

<https://www.norfolk.gov.uk/care-support-and-health/support-for-living-independently/money-and-benefits/money-support-service>

The Incontinence Team are not able to prescribe pull up pants which give people independence. Instead, they prescribe the sit in pads or wrap around pads that require someone else to fit them. Also, you can only get a prescription for 4 items per day. There is a gap in provision for incontinence products children aged 7-15. They are too big for the younger aged products but too small for the adult products. Incontinence remains a taboo subject and there needs to be more acknowledgement of the issues around it.

**Kristen Hall, Communications and Engagement Lead- Programmes, Norfolk Clinical Commissioning Group**

Kirsten has recently joined the CCG as part of the engagement and communications team. They are working to establish a regular dialogue for health and social care information that is important for Carers. They have a Children and Young person’s lead that also looks after Special Education Needs within the communications team.

The issues with incontinence products were shared with Kristen so she can feedback. Carers are spending £40 for a 3-week provision of pull up pants. Should be a system in place for Carers to be able to pay the difference between the types of pads if they are not available on prescription. Parent Carers are told to hydrate their young people; however, they can only go to the toilet 4 times a day with the current allocated provisions of 4 pads a day. There isn’t just the cost of the products to consider but the cost of washing/drying items and the extra work involved which isn’t usually considered.

Shops and public spaces should have sufficient disabled toilets. Changing Places are designed for people who cannot, or find it difficult, to use a standard accessible toilet. The government has £30 million available to district councils to establish more Changing Places across the UK. The focus of this grant is for new Changing Places in existing buildings. Norfolk County Council isn’t eligible to apply for this grant, but they have committed £600,000 to establish up to eight facilities in their own properties, such as some of their libraries. Changing places are also important for tourism purposes. Norfolk County Council have been consulting with Carers about Changing Places. Parent Carers often have to use the back of their car or toilet floors to change their children as the changing area provided is not suitable/too small. There should be a way for companies to be compensated for building changing places.

It was asked if Carers are provided with a meal if the person they are caring for is in hospital? It was felt that if you are caring for someone full time at hospital you should be provided with at least one meal from the trolley. Some hospitals give concessions on food and parking such as the Norfolk and Norwich University Hospital. The Paediatrics ward at Addenbrookes have a parent’s room with a microwave, kettle and toaster that parents can use. This also provides parents with the chance to speak to one another.

Malcolm asked about the Mental Health hub in Norwich. He was very involved with it at the start but then heard nothing. The REST service is now up and running but this was not communicated. More information can be found at <https://restnorwich.co.uk/>

There used to regular contact and meetings with the 5 CCG’s before they merged into one. The CCG’s regularly explained what they were doing, where the finances were being directed and why. They are now changing into an integrated care system which is scheduled for next spring. Kristen said the communication and engagement team at the CCG has expanded and is looking to re-engage with different groups.

Concerns that the CCG are looking at topics but not localities and whether there will be communication between the groups. People don’t fit into one box and therefore a locality-based approach was felt to be more helpful as you can see the whole picture from a number of perspectives, whereas it may be limiting focussing on themes.

Rosie explained that Healthwatch look at things in terms of localities but also look at topics. Healthwatch and the CCG communications team are due to meet and will be discussing how they map feedback.

**Action:** Kristen to feedback the preference of locality bases.

**Action**: Kristen to put Tracy in contact with the Children’s Lead in the communications team.

Kristen is interested to hear what information Carers want and can feedback information to the CCG.

If the cared for person is getting the support that they need, then there is less for the Carer to be concerned about.

Kristen wanted to stress the importance of the ‘flu vaccines and covid boosters and wanted to find out whether Carers have been able to access the vaccinations they need. One Carer said they’ve been contacted about their Covid booster but not about the flu, despite being in their 70s. Another Carer was notified and has booked their flu vaccination, but it is too soon for their Covid booster. A Carer shared that they were only able to get their vaccine at the same time as the person that they are caring for as they pointed out that they are a Carer. Even though they are registered with their practice as a Carer, they said that they are not able to cross reference. Another person’s partner is immuno-suppressed so they should be prioritised to receive the booster vaccine, however this has not happened.

It was acknowledged that every GP surgery is different. A GP surgery has a message when you call saying that they are unable to speak to you about the vaccine. But another GP helped with a query in relation to the booster vaccination. You have to wait 6 months until your booster vaccine. You will only receive a text/letter with information about the booster vaccine when it has been 6 months since your second vaccination. The NHS are going to send a letter to Carers to encourage them to get their booster vaccine. The letter will also encourage Carers to register as a Carer with their GP.

**You said, we did**

* Carers Emergency Planning:  The form Carers helped co produce is now live; some issues raised regarding functionality and the form not allowing Carers to log back in and update information. Norfolk County Council IT team are confident that they can build something into their system to enable Carers to report changes to their plans but it’s very early days and unlikely to take place until later this year. For the time being Carers will need to follow the same process of completing the form from scratch, to report changes; but hopefully Norfolk County Council can achieve a resolution to this. James wanted to ensure Carers are kept updated, the Council are listening and take Carers feedback seriously and are working to find a solution.
* Hospital transport. Carers haven’t been allowed to travel with the person they care for in hospital transport particularly to the Norfolk and Norwich University Hospital. Carers Voice has raised this with the Patient Experience Team at the NNUH and they are looking to work with ERS patient transport, to raise awareness. This is still ongoing.
* Respite. Question raised about respite to James Bullion at Healthwatch AGM

A question was asked about what happens in the event that the respite is cancelled after the Carer has planned for it (booked a hotel, transport etc). It was suggested that the respite provider is contacted. In recent experience, hotels have been able to reschedule.

Stacey reported the current care crisis may be having an effect on bookable respite. Norfolk County Council are offering emergency respite in care homes as there are not enough care workers to provide it at home. The Swift service is picking up a lot of the work resulting from a lack of care workers

* *North Carers Meeting.* Carers Voice have been supporting one of the Ambassadors to arrange a meeting with professionals working with Carers in North Norfolk to see how they can come together to support Carers.
* *Carers have said that they want more contact with the CCG*. Carers Voice are building a relationship with Kristen Hall, Communications and Engagement Lead – Programmes and she is attending locality meetings
* *Discharge to Assess.* Carers have been liaising with the discharge to assess teams. Carers have been working with the Discharge Improvement Clinical Lead at the Norfolk and Norwich University Hospital to develop a next of kin/Carers/significant other.
* Carers have been working with Carers Matter Norfolk to see how Carers can be involved in the recruitment of new staff.
* Carers Matter Norfolk have used the feedback received from Carers to produce a welcome pack of information that will be given to Carers who are referred to the service.

**Carer Involvement Opportunities:**

**East of England Ambulance Service**

The East of England Ambulance Service are keen to hear feedback from anyone who has used their service recently for themselves or the person they care for. This is part of their ongoing patient and public involvement agendas and their newly co-produced patient and public involvement strategy. They would really value the opportunity to hear your experiences and views on the East of England Ambulance Service. You can feedback by:

* Completing their survey- <https://www.eastamb.nhs.uk/contact-us/patient-surveys.htm>
* Sending comments to their PALS team <https://www.eastamb.nhs.uk/contact-us/pals.htm>
* **By phone:** 0800 028 3382 (freephone) or 01234 243320.
* **By email:** feedback@eastamb.nhs.uk
* **By post**East of England Ambulance Service NHS Trust (EEAST)
Patient Experience Team
Hammond Road
Bedford
MK41 0RG

They are also keen to hear experiences through a 1:1 feedback interview either face to face or virtually, whether the experience is good or bad. The interview will be led by you with no set questions. It will allow them to hear your experience in a way that works best for you and to go onto greater depth than the patient surveys. With the participant’s permission they record these interviews, to enable them to share with their trust Board and staff to enable them to learn directly from your experience and improve.

Please contact involvement@eastamb.nhs.uk if you would like to take part in an interview.

Stacy shared a recent experience she had with calling 999 for someone who was having a suspected heart attack. The ambulance service said that there could be a 3 hour wait, depending on whether they had anything more severe come in. In the end, a family member drove them to the hospital. Jill has had recent positive experiences where the ambulance has arrived in under 20 minutes. It depends on where the ambulance is at the time. A Carer shared their past experience with the ambulance service where the person they care for was on the floor for 6 hours. They have never had an ambulance arrive in under 2 hours. There are also issues with the time it takes for district nurses to arrive. They have had to wait an average 4-5 hours for them to arrive.

**Short term bed offer team, Norfolk County Council**

Short term beds are when someone in hospital no longer needs hospital care but cannot be discharged without longer term plans being put in place. They transfer to a care home usually for a 6-week period while a long-term care package is put in place. Norfolk County Council are looking for feedback and would like to ask Carers 3 simple questions about their experience.

**Sandringham Christmas Market Trip:**

Caring Together are arranging a trip to the Sandringham Christmas Market for Bereaved Carers. This is taking place on Friday 19th November. They are looking at a bus from Norwich to Sandringham with a few stops on the way.

**Action:** Catherine to ask Caring Together if the trip is open to Parent Carers

**Action:** Catherine to share Eventbrite link when it has been published.

**All Age Carers Strategy**

The last Carers strategy was from 2014-17. This is the first time there has been an All-Age Carers Strategy that covers Norfolk and Waveney. Carers Voice will lead the first part of the strategy to find out what Carers want and need from health and social care to support their needs in the future.

Carers Voice have been working with Carers groups to co-produce the strategy including West Norfolk Carers, Young Carers and families, Parent Carers, Young Adult Carers, Carers Ambassadors and Healthwatch. It has been interesting to incorporate everyone’s ideas as these have varied between group of Carers. The official launch of the survey will be week commencing 1st November with focus groups and workshops to follow.

Carers have suggested focus groups on mental health and neurological issues. Stacy said that a focus group on the issues around the current care crisis may be worthwhile. There are 450 Carers who have not been vaccinated so can no longer work in care and 50 care packages that have been returned to Norfolk County Council. Family Carer Practitioners are advising Carers to keep the care package they currently have as the likelihood of getting another care package is very low. This is having a major impact on Carers and the people they care for. It was reiterated that if the people Carers are caring for are being supported, then this reduces the stress on the Carer. The All-Age Strategy is looking at planning for services over the next 3 years.

It was felt that Carers are expected to carry the burden of care. Even if Carers are willing to do a lot of the care, they may not be able to due to their physical health. They may also have caring roles for children and parents. Recognition that Carers may care for more than one person such as sandwich Carers, is important.

**Professionals:**

**Stacy Robertson, Carers Matter Norfolk**

Carers Matter Norfolk are recruiting for 3 Family Carer Practitioners for the adult service. These will be for Norwich, South and East Norfolk. They are also recruiting a Welfare Rights and Benefits Advisor. Additionally, they are recruiting Family Support Workers for the Young Carers and Families service. There will be two separate groups of community teams that will work as part of the two different services. There will however be a cross over between the services when a family is being supported.

The biggest issue at the moment is the lack of care workers and unfulfilled Care Packages. There is a big reliance on the Swifts service.

**Update from James Stewart**

*Safeguarding:* Following on from meetings with Carers, supported by Cares Voice, they are looking at launching a campaign in early 2022 to reach out to Carers and those supporting them from a range of agencies/ organisations, to educate on the different types of abuse, support available and how to access it.  Carers who have previously supported Norfolk County Council around their Safeguarding planning will be inputting into this.

*Replacement care*: This continues to be an area which Norfolk County Council recognises can be frustrating for Carers, and not being able to advance book replacement care. They are in the process of recruiting a commissioning manager to tackle this area and when in a position to take this forward, would welcome the chance to have a focus group of Carers, to help with shaping this support offer.

*Website update*: They are currently working on reviewing current web content, with a view to making it more accessible and informative for Carers. When this starts to take shape, they would like to share it with Carers to find out the key information they feel would benefit them the most in respect of information and advice.

Stacy said that the new referral form on the Norfolk County Council has changed and now is very long with many questions. It was felt that the information requested in the form would be repeated in the needs assessment. The length of the form may deter Carers from completing it if they want to request a needs assessment.

**Action:** Catherine to share feedback with James Stewart.

Norfolk County Council are keen to hear from Carers about what training they want. Due to Carers responsibilities being different, an online forum may be the best in terms of convenience, although this might not suit all topics such as manual handling. There was a consensus that there is only so much training you can do and it comes down to time available.

A dementia training course was suggested covering topics such as how to spot the signs, how the condition will change, what to expect and how to respond.

There was also the suggestion of early training for Parent Carers around mental health issues and how best to support their children and how to address issues.

It was felt that early training for certain conditions would be very useful, so Carers have all the information at the start.

**Next meeting: Date to be confirmed**