

MEETING NOTES:	Carers Partnership Board
DATE:	25 th January 2024
LOCATION:	Truro Community Library and on Microsoft Teams

ATTENDANCE

Name	Position	Organisation
Sandra Ward (SW) (Co-Chair in the Chair)	Parent Carer of lady with complex self-needs and autism, sandwich carer of four elderly parents & Director	Parent Carers Cornwall
John Bastin (JB) (Co-Chair)	Cornwall Councillor and Chair of Health and Adult Social Care Overview and Scrutiny Committee	Cornwall Council
Mike Hooper (MH)	Partnership Boards Officer	Healthwatch Cornwall
Robert O'Leary (RO)	Partnership Boards Lived Experience Officer	Healthwatch Cornwall
Amanda Wilton (AW)	Derriford Patient Council & Carer for an adult with profound and multiple Learning Disabilities	University Hospitals Plymouth NHS Trust
Ben Seamarks (BS)	Strategic Commissioning Manager	Cornwall Council
Chris Watkin (CW)	Project Lead	Cornwall Carers Service
Debbie Gilbert (DG)	Chief Executive	Healthwatch Cornwall
Gayle Andrews (GA)	Senior Area Co Ordinator	FILO project
Jayne Price (JP)	Contract Lead for The Carers Service	CRCC
Juliana O'Neill (JO)	Way Finder	Cornwall Memory Cafe
Kelvin Yates (KY)	Deputy Chief Executive	Age UK Cornwall and Isles of Scilly
Kelvyn Hipperson (KH)	Chief Digital & Information Officer	NHS Cornwall and the Isles of Scilly ICB
Lynda Berry	Carer and Director	Constantine Carers Group and Cornwall Partners in Policy Making
Pauline Hardinges (PH)	Ex-Carer, current part-time carer & Treasurer	Liskeard Memory Café
Sally Mollard (SM)	Ex Carer & Secretary	Liskeard Memory Café
Wendy Gauntlett (WG)	Carer	Penzance Carers Group, Penzance Carers Forum and Adult Safeguarding Board
Zoe Locke (ZL)	Head of Patient Experience and Carers Lead	CFT

APOLOGIES

Name	Position	Organisation
Alison Short	Advocacy Coordinator, Cornwall and the Isles of Scilly	The Advocacy People
Bernie DeLord	Director	Promas Caring for People CIC
Jenny Tarvit	Promas Caring for People CIC	Director
Joanna Dobson	Patient Engagement Manager	Royal Cornwall Hospitals NHS Trust
Kate Alcock	Head of Strategic Commissioning – Older People, Physical Disability and Carers	Cornwall Council
Neil Lindsay		Bodmin & Wadebridge Carers Groups

ACTION LOG

Meeting	ACTIONS CARRIED FORWARD	RESPONSIBLE	STATUS
25/01/24	Bereavement Planning and Support for Parent Carers	SW / PB Team	To be scheduled
25/01/24	Making the Board as Effective as Possible	PB Team	To be scheduled.
25/01/24	PenARC Patient and Public Involvement and Engagement Team, Exeter University	BSu	25 April meeting.
25/01/24	FILO project presentation.	GA	25 April meeting.
25/01/24	Review of Overnight Respite Provision for Working Age Adults	JM	Update to 25 April meeting. DEFERRED.
20/07/23	GP identification of carers.	CM	Updates as appropriate.
20/07/23 04/05/23	Investigate opportunities for Carers Forums.	KA	Ongoing.
04/05/23 26/01/23	Continuing Healthcare group updates.	PH / JP / CM	Updates as appropriate.
04/05/23 11/08/22	Update on Day Opportunities	EB	The report was circulated to the Board prior to the meeting
11/08/22	Carers Voices Partnership – how it will link with the Board and content of reports.	ZL / MH	Updates as appropriate.
11/08/22	Update on sharing of patient information across IT systems.	KH	Ongoing. Updates as per progress.

	Item	Action
1	<p>Teams Guidance and Meeting Etiquette</p>	
	<p>SW welcomed everyone to the meeting and asked that members online use the 'raise hand' function if they wished to speak. Use of the chat function was encouraged in order to allow the meeting to flow.</p> <p>Expectations with regard to meeting etiquette were detailed on page 3 of the agenda.</p> <p>There were "round table" introductions and MH read out apologies received, as detailed above.</p>	
2	<p>Minutes of the Meeting held on 19 October 2023, Actions and Matters Arising Actions from Previous Meetings</p>	
	<p>The Chair proposed that the minutes of the previous meeting be confirmed as a true record. The Board agreed that the minutes were a true record.</p> <p>The Chair shared updates on actions from previous meetings:</p> <ul style="list-style-type: none"> • Jayne Price will provide detail of what constitutes a Carers Crisis within her Carers Service agenda item 6. • Support for self-employed carers – Jayne Price will be updating in agenda item 6 and information is available on the website. • Carers Strategy Review – Update on work stemming from structured interviews with carers. Ben Seamarks will update in agenda item 4. • Review of Overnight Respite Provision for Working Age Adults – Jon Manzoni has requested to feedback at the next meeting in April on the engagement with Carers and people who access overnight respite services, including comments received from the Board and the impact on future services. SW asked if the Board agree to that being on the April agenda. The Board agreed. 	<p>25 April 2024 agenda item.</p>

	<ul style="list-style-type: none"> • GP identification of Carers – No update available. • Identify upward reporting structure and opportunities for Carers Forums or a replacement version. These can be covered within the final agenda item when we'll discuss what is needed to make the Board as effective as possible. To be discussed in item 8 – open discussion • Continuing Healthcare group – No update available. • Day Opportunities – This report was circulated to the Board on 24th January 2024. • Carers Voices Partnership – Zoe Locke to update later in the meeting. • The Chair said that Kelvyn Hipperson was in attendance and would update on the sharing of patient information across IT systems, should the Board agree. The Board agreed. <p>There were no matters arising.</p>	
<p>3</p>	<p>Updates from the Co-Chairs</p>	
	<p>Councillor John Bastin</p> <p>JB thank Kelvyn Hipperson for his attendance. The need to improve the sharing of data across NHS systems and between Devon and Cornwall had been raised by the Board for many years so it was good to see that progress was being made.</p> <p>JB sent MH current information on the Measles, Mumps and Rubella vaccination, which he circulated to members via email. JB added that levels of measles in Cornwall is rising and the information may be helpful for those who have not been vaccinated and their carers.</p> <p>Sandra Ward</p> <p>SW informed members that the Parent Carers Cornwall report is now available and was distributed to members prior to the meeting. On the Parent Carers Cornwall website there is a new online Neurodiversity Hub page which holds information and advice for both families and professionals. It is already receiving</p>	

	<p>great feedback from parents and carers.</p> <p>Parent Carers Cornwall remain extremely busy, in March there is the next main information event at the Eden Project, with over 20 service providers attending.</p> <p>There is a lot of work being undertaken within the Epilepsy Service. The Epilepsy Action group called Step Together are creating a toolkit to redefine what the Epilepsy Service offers in Cornwall, particularly in relation to Learning Disabilities.</p> <p>SW is also linking in with the Epilepsy Team that operate from the Treliske, specifically for those people with Epilepsy only. Working with the Paediatric Team, the new Cornwall Parent Carers Epilepsy Support Group is available on Facebook for people caring for those with Epilepsy of <u>any</u> age. It's a peer support group that is condition specific and although SW only created this in mid-January 2024, it already has 23 members.</p> <p>MH said that he had attended a meeting specifically from the Learning Disability aspect with the Lead for the Epilepsy project that SW updated members on. MH acknowledged it appeared to be an excellent piece of work.</p>	
<p>4</p>	<p>Updates from Members and Commissioners</p>	
	<p>The Chair invited updates from the individuals and organisations represented.</p> <p>Day Opportunities</p> <p>MH directed members to the information provided by Cheryl Bridges, Strategic Commissioning Manager, People Commissioning (Care & Wellbeing), Cornwall Council, which was included within the Updates from Members and Commissioners report that was circulated to members on 24th January click here.</p> <p>SW commented that many carers that have joined the meeting online are affected by the Day Opportunities available to them.</p> <p>Structured interview with Carers</p> <p>BS said that many on the Board will remember from the October meeting, that during much of Autumn structured interviews were</p>	

undertaken by service leads with people who have lived experience of being a carer and professionals across the system, inline with the Cornwall Care for Carers Strategy Outcomes.

BS reported that engagement numbers were slightly lower than anticipated, however, those that did engage provided some very candid, thought provoking and meaningful feedback in relation to the how the system is honouring their own identified desired outcomes. BS reported that the feedback report currently contains 17+ pages of direct quotes from those involved in the engagement process and that the analysis has not yet been through Cornwall Council's internal governance procedures, meaning there are some constraints on the ability to share details with the members today. However, there were significant cultural challenges identified during the conversations. Particularly in relation to the way in which Cornwall Council are working with carers to understand the extent of their caring and supportive roles and taking onboard their views. Robust feedback was received on the sufficiency of short term and respite care, but also regarding Cornwall Council's conceptual view of what the system perceives as a break from caring. There was a lot of call for an improvement to the system for carers wellbeing support and short term respite, that carers reported create stress, often having logistical issues in arranging and managing them. An outcome has been identified for respecting carers as experts in their roles, as well as an issue with the system wide (all health and social care partners) approach for listening to carers.

There were comments regarding employed carers, the robust feedback focused on supporting employers to understand the impact of employees' caring roles.

BS will pull together a set of proposals from the detailed feedback, that will be submitted through internal governance within the next ten days. Once agreed, they will be shared with the board to facilitate a second wave of conversations accordingly.

BS thanked Jayne and Chris, and all their colleagues in the Carers Service Team, regarding the 'Industrial' amount of work required to eliminate the historic backlog of workflow steps for the carers service. Credit is due to them and their team as they cleared the backlog by the end of December – thank you.

BS also touched on The Urgent and Elective Care Support Fund. It was a short term non-recurring amount of funding from Central

Government that was received in late November following a successful bid from Cornwall.

The schemes are now mobilising and BS asked carers to note that a block purchase of respite beds are available to book, one in each locality, explicitly there for the benefit of carers. Opportunities are available to extend the booking if demand outstrips supply.

Sharing of Patient Information across IT systems

Kelvyn Hipperson introduced himself to the Board. He informed members that in his role he works within the IT service that covers RCHT, CFT and Integrated Care Board.

KH gave a presentation entitled 'Our Digital Transformation Journey'. [Click here](#) to view it.

Questions and Comments

RO asked KH to clarify the involvement from the Third Sector. KH informed members that there is a Digital Transformation Board attended by partners across the system. The Deputy Chief Executive of Age UK, who helps to co ordinate across the different third sectors, joins the Board meetings. At the meeting in January 2024, it was reiterated that Third Sectors are keen to move forward with the concept of their case management systems joining up elements of their platform(s) with the Health Sector and to support the broader health provision for people. This will start small and build over the next few years.

SW asked, on parents and carers behalf, if this means that they will no longer be required to tell their story at every hospital visit. KH informed members that this example is often used as identifying what is wrong at the moment. Unfortunately, due to the different systems, replacing them all in one go is not an option, so the work will focus on joining up the systems step by step, gradually reducing the need for repeating the information and eventually reaching the point where it will only need to be shared once. SW said this was essential and should result in more co-ordinated care plans. The Step Together project discussion identified that care plans are often disjointed, resulting in many that do not have joined up information. To have one plan of care that follows the person to wherever the care and support is being provided, even if this is out of Cornwall, such as for neurodiverse

individuals who need to travel to Bristol, would be very good. KH responded that there is currently a pilot with treatment escalation plans between Devon and Cornwall, who agree a common format.

Currently there is work underway with GP Practices in East Cornwall joining up with Devon colleagues already on the pilot. This will eventually be rolled out across Cornwall.

The ICB Chief Medical Officer is keen to move onto involving broader treatment plans. This will involve work to develop a consistent approach. Once achieved, KH would like this to be added to Devon and Cornwall Care Records to be available to all who need to know.

SW thanked KH for his attendance and presentation.

Royal Partnership NS Foundation Trust – Patient Experience Team update

ZL – explained their role of Carers Lead to the Board. Although the team is small, there is currently a business plan underway, to hopefully employ more members.

ZL recently met with the organisation's performance team, who share a report on a monthly basis. It was always assumed that the report included the number of carers identified each month, on scrutiny this was found not to be the case and when reviewing records of carers within the current RIO system it was discovered the process has not been completed correctly.

Carers have not been removed from the system when patients have been discharged from services, therefore, when looking at involving the carer, data the numbers have now risen greatly, resulting in thousands of carers showing on the system who may no longer be in the role. This will be a huge piece of work for the organisation.

ZL will be commencing focus groups in the county and is calling for Board members to inform on any potential interest in attending the groups that will help capture the correct data and identify how people should be asked if they are a carer. In conversations with colleagues out of County, the fact that people do not always recognise themselves as carers was acknowledged.

Staff training will be available and if any Board members would like to be involved in the sessions they are advised to make contact with ZL.

It is acknowledged in the organisation that there is a lot of learning required.

Questions and Comments

ZL asked for clarity on who completes Carers Assessments. BS said these are completed by the Carers Service, also front line Social Workers do undertake them, especially in conjunction with Support Planning Assessments for people with support needs.

JP and SW offered to be involved in the training.

JP asked if ZL's team members would benefit from some workshops to clarify the changes to the Carers Assessment referrals, since the system has changed, and RIO is no longer the route. ZL agreed workshops would be of benefit for team members. JP also offered support and working together on some assessments. ZL informed members that the team would also be looking to create a policy and any help would be greatly received.

RO offered to be involved in the focus groups.

WG commented that identifying carers is a concern and the assessments seem to be dominating the work of the Carers Support Service, which is impacting on other responsibilities. Could ZL's team help with this? ZL responded that the Royal Cornwall Hospital Trust Carers Passport will be adapted for the Community services to hold more relevant information. The need for better signposting is recognised and Cornwall Partnership NHS Foundation Trust are looking to start some 'Carer's Corners' to gather information and improve the signposting.

WG informed the Board that there have been several attempts at contact with Disability Cornwall with no success, messages had not been followed up. Information has been received that they are very short staffed, are they still operating? JP advised that Disability Cornwall is the front door to the Carers Service and run the advice line. They are currently recruiting but this should not impact the service delivery. WG to share contact details with JP for follow up and further discussion outside of the meeting.

	<p>SW thanked ZL for attending and presenting.</p>	
<p>5</p>	<p>Update on the Informal Carers Support Service</p>	
	<p>Slides had been shared with the Board prior to the meeting. Click here to view.</p> <p>JP acknowledged the work the team have undertake to clear the backlog of Carers Service workflow. There will be a piece of work undertaken to feedback on the learning from this work and it will be shared with the Board in due course.</p> <p>JP shared a slide showing the commissioning responsibility of developing guidance for employers to be carer aware. There are a range of tools available for employers, from identifying carers to supporting them to remain in work and the benefits this can offer to employers.</p> <p>The next piece of work is to expand on the employer support, further developing the flexible working policies, focusing on partners who are some of the largest employers in Cornwall such as Health and Social Care, and to include the Carers Passport within their own flexible working arrangements.</p> <p>Over February and March 2024 there will be a campaign across the Carers Support Service website that promotes the Carers Passport as good practice, along with a webpage that will provide information for employers, promoting how they can better support Carers in their employment. This is a priority for the Carers Support Service and is in line with the Carer’s Leave Act, which will come into full force in April 2024.</p> <p>JP shared slides and information on ‘What is a Carer in Crisis?’ A Carer in Crisis is identified as a carer who is close to or is experiencing, ‘Burnout’ or exhaustion. Often reaching the end of their reserves, caused by excess stress over a period of time. It can cause many feelings that result in compassion fatigue or losing the will to care.</p> <p>The many feelings, both physical and emotional, are recognised symptoms that can indicate Carer Fatigue, often leading to Carer self-neglect, impacting on many aspects of day to day including sleep and mood. It is acknowledged that often consistent or long</p>	

term support is essential to prevent a Crisis.

JP shared further in-depth detail on identifying symptoms of Carer Crisis. A Carer's comment was shared.

Information will be available on the Carers Support website in the near future that can help people to identify if they are approaching or experiencing Care Crisis.

SW acknowledged that Carers Crisis is a really important subject, recognising symptoms of Crisis is essential for all carers.

AW acknowledged the great work and asked if the details of the slides will be available as a leaflet. JP responded that the plan is for a refined fact sheet for Carers to recognise the symptoms. That will become available on the Carers Support website and as a handout.

WG commented that it was an excellent piece of work. A leaflet will be very handy.

BS commented that this is a powerful, succinct and important piece of work for informing and supporting people to recognise 'burnout' and offered to help with the design work for the leaflets.

RO commented that when recently attending the Newquay Jobcentre Plus 55 event, a gentleman who had given up working to care for his wife over a five year period had not had a lot of support in his caring journey and had reached burnout. The gentleman also shared that it was after his caring role ended, when his wife had passed, that the pressure mounted significantly from relevant authorities such as Department of Work and Pensions, along with general financial pressures. What support is available for people in this position of transition and adjustment from leaving their caring journey? JP said that the Carers Support does have a small remit to help carers in their next steps on leaving their caring role and there are many considerations in that time of recovery. It's essential to understand what recovery looks like for the individual following their loss and the trauma this causes. The commitment needs to be across the County to support people in a trauma informed way and identifying all provisions to support their physical and emotional wellbeing.

SW commented that this is a really important issue and needs to be revisited in future meetings to explore the detail further.

<p>7</p>	<p>Deferral of agenda item</p>	
	<p>Due to time restraints, the Chair proposed that the agenda item 'Open Discussion – Making the Board as Effective as Possible' be deferred to a future meeting. The Board agreed.</p> <p>MH suggested that prior to the item being considered, a survey could be sent to Board members to gauge views and ideas on how the Board can develop.</p>	<p>Item to be scheduled</p>
<p>8</p>	<p>Bereavement Planning and Support for Parent Carers</p>	
	<p>SW informed members that this item was regarding to emergency planning. SW is a member of the Learning Disability and Autism Programme Board, where there had been consideration of crisis and emergency planning, particularly in the case of parent carers for young people with Learning Disabilities. Discussions were held and feedback received from parent carers of those with very complex health needs involving comorbidities, many medications and often visits to Bristol for hospital treatment.</p> <p>The carers themselves are very unlikely to work in full time employment. Often their children's life expectancy is low, which makes long term planning for their service need in health, care and education very difficult.</p> <p>Amongst these specific groups of carers there is much fear that they will die before their offspring. Provision to support their young people when they have lost their parent carers is reducing, with some closures of facilities already seen. It is a real concern to many people.</p> <p>SW has discussed with BS that there needs to be a chapter within the Carers Strategy to include the complexities that the group experience.</p> <p>JP thanked SW for her very honest words. Meaningful support must be discussed within the Partnership Board.</p> <p>AW acknowledged how powerful the statement is and the importance of further discussions and support going forward to</p>	

	<p>help with the very difficult decisions.</p> <p>MH asked if SW had received any feedback from the Learning Disability and Autism Programme Board as the meeting set for the end of January, when it was to be an agenda item had been cancelled. SW confirmed that no feedback had been received to date.</p> <p>WG thanked SW for her heartfelt comments and shared her personal experience concerning her grandson.</p> <p>LB supported SW in the statement made and shared her personal experience and the importance of the support.</p> <p>BS agreed and thanked SW for her words that are very important, there tends to be much trepidation around honest and open dialogue regarding planning for death and support needs.</p> <p>RO fully supported the work needed and commented that in a previous Social Prescriber role he had seen circumstances where the care fell to grandparents who were not in good health themselves. Planning is very important.</p> <p>SW thanked everyone for their comments.</p> <p>The Board agreed that the matter be included in its work programme to ensure future consideration.</p>	<p>To be scheduled</p>
<p>9</p>	<p>Any Other Business</p>	
	<p>JO asked if there were to be any further Ageing Well Board meetings following the workshops. RO said that the feedback from the workshops allowed the opportunity to understand an element of lived experiences and from there shaping the format to ensure the best support has been undertaken. There is cross-organisational involvement, the difficulty has been encouraging the input from those with lived experience. The next Older Persons Partnership Board meeting will be on 15th February 2024. He added that, moving forward, there are thoughts that the format should be less formal and the title Positively Ageing Cornwall may be used moving forward.</p> <p>MH emphasised the importance of the partnership element, working together to involve people with lived experience.</p>	

	JO commented that their team can help to promote this.	
10	Next meeting	
	2pm on 25 th April on Microsoft Teams.	