



North Yorkshire Carers Forum - Minutes

Thursday 27th November 2014

11:30 – 14:00

Disability Action Harrogate.

Carers	
Present:	
Ian Parkinson (IP) (Chair)	
Hazel Griffiths (HG)	
Jane Chilton (JC)	
Sheila Constable (SC)	
Lindsay Allen (LA)	
Elizabeth Ruddle (ER)	
Mike Spinney (MS)	
Alayne Holmes (AH)	
Adrian Smith (AS)	
Apologies:	
None received	

NYCC/Other Officials	
Present:	
Avril Hunter – Strategic Commissioning Manager (AV)	
Elaine Brookes – Commissioning and Change Implementation Officer (EB)	
James Zinyongo Social Care Assessor (JZ)	
Ruth Chamberlin Commissioning and Change Implementation Officer (RC)	
Linda Owen Carers resource Centre Harrogate and Craven (LO)	

		For action or note by
1	Introduction and update from the Chair	
	(IP joined the meeting after Matters Arising and continued to chair the meeting) Chairs update IP had contacted various government departments to seek clarification around the new £72,000 care cost caps that will come in force in April 2016 but no one can give clear answers about the	

	<p>impact on working age adults and under 18s . AH explained that this could be because these changes were not coming in until 2016 and hence focus is on the changes that need to be implemented in 2015.</p> <p>IP had also attended a very interesting and thought provoking Employment Event in York, focusing on people with LD and supported employment .A useful website www.learningdisability.org.uk . IP was particularly impressed by Dave Barker who was involved in the day. IP has his contact details</p> <p>Healthwatch update</p> <p>One of the groups role is to review services within the catchment area .This month they have been involved in a review of Rivermead Nursing home in Malton . If, during the reviews the group note any serious concerns they then flag up these concerns to the CQC .</p> <p>Vale of York CCG is currently doing a a Pharmaceutical Needs Assessment Consultation. IP encouraged people present at the Forum , to get involved in this process if they can ,as the meeting he attended was rather top heavy with health professionals .There is a website www.ny.partnership/pna.</p>	
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2	Minutes and matters arising	
	<p>AH commenced chairing the meeting as IP was running late.</p> <p>Minutes of the previous meeting</p> <p>AH drew the meetings attention to a presentation that IP had made, detailing his experiences as a carer. The presentation had been circulated with the Carers Forum minutes and agenda for this meeting. Also people may wish to read a poem that IP had read out at the September meeting. The words are from Lynne Elwell, headed "Workers in 'Serviceland' often ask Where are the parents?". IP felt that the sentiments were poignant, illustrating the demands on parents of children who require care and caring in general</p> <p>AH and EB as the only people present at the September meeting agreed the Minutes of the last meeting held on 3rd of September 2014.</p> <p>Matters arising AH updated the meeting on the North Yorkshire Care and Support Where I Live Strategy.</p> <p>Consultation has closed and people seem positive of the initiative. Findings from the Consultation will be passed onto the Councillors and Senior Managers in NYCC.</p> <p>New carers Information Booklets</p> <p>They are now available and are being rolled out across the county.</p>	AV

	<p>RC informed the group that there is a good website with information relating to dementia atdementia.org .uk</p>	
3	Feedback from HG	
	<p>HG had attended an event where . Janet Wright from Leeds Council introduced a new initiative around monitoring the quality of care received by people with LD who are cared for in residential units etc. There will be a team of “Checkers” including council staff, family carers, and advocates. Janet had received mixed responses to her requests to visit the units in question. Some welcome the visits and were very open. Others stated that she can only visit if their Regional Director was present. HG feels this is a positive initiative and would like to see NYCC developing a similar model, especially in light of Winterbourne.</p> <p>The meeting discussed the new Care Act. The Act focuses on Prevention, services need to get involved earlier rather than further down the carer road as happens at present. The Act places the Carer on the same footing as the Cared for. Concerns were raised is there enough money in the system to implement the Act. Is there enough staff to cope with the increase carers assessments? Staff will need training in the New Act. Also better information is needed for carers. HG asked what work was happening in NYCC to help support family carers and to get ready for the new Act. (Both AH and EB reassured the meeting that within NYCC there is preparation work going ahead in readiness for the implementation of the Act.) She also raised the issues for carers around the importance of carers assessments / reviews around annual health checks HG also feedback to the meeting that she was going to a meeting in London regarding Safeguarding in Hospital and she for one is an advocate of using CCTV in hospitals and other settings. She appreciated that this is a Human Rights issue for staff and service users but the safeguarding of vulnerable people should be the priority. She feels strongly that Commissioners should not be funding residential placements hundreds of miles away from family and friends. Money should be invested in creating local services. MS added that CQC are publishing guidelines around covert CCTV. He also informed the meeting that he felt the CQC has made great improvements in the way the inspect .For example in the past the Inspectors could inspect LD units without any knowledge of LD. Now LD inspections are made by an Inspector with LD experience this allows them to communication with people who have communication problems. MS himself is now involved with LD inspections, he also noted that the CQC looks for good practice as</p>	

	<p>well as bad. In the future homes will display there CQC rating on their doors /signs etc.</p>	
4	Update on Dementia Strategy	
	<p>Before RC updated the meeting re the Dementia Strategy she spoke briefly about NYCC Autism Strategy. Stating that NYCC has done a lot of work in this are training staff etc. AS felt that different services should not be arguing over pots of money that all illnesses should be funded equally.</p> <p>Dementia Strategy Dementia is a National issue with around 10,000 people in NYCC catchment are living with dementia. Will rise to 14,000 in the coming years. National policy of 2009 National Dementia Strategy remains in place no plans to update it. Focus on diagnoses /treatments /carers /social care .also the link with Down Syndrome and dementia and early onset dementia. A debate took place around the ethics of paying GPs to diagnosing people with dementia. In 2010 there was a Prime minister Challenge to create a dementia Friendly Communities to help support people living with dementia e.g. shop and bank staff given awareness training etc. This will help more people to get out and about . It is estimated that ¾ of people living in residential homes have memory loss problems.. CQC published a report “Falling through the Cracks” that highlight the issues of how people with dementia are cared for in Hospitals. At a Local level a multiagency dementia strategy jointly with York. Has been developed based on the national strategy and is due to be refreshed soon. It looks at staff training with in the councils, creating Dementia Champions in the work teams. Negotiating new contracts with Domiciliary and Residential providers. New dementia support groups out in the community with emphasis on reaching out more to find more people. Dementia Forward covers Selby, Harrogate and Hamilton and Richmondshire. aking Space covers Scarborough, Whitby and Ryedale and Craven. Work is on-going around making hospitals more user friendly .Harrogate hospital has done a lot of work in this area e.g. painting all toilet doors a distinctive colour.. Extra Care schemes improve the environment to assist people with dementia. There is a national campaign for Dementia Friends The aim is to give people a basic training in the general principles of the effective way to support someone with dementia A report called Road Less Rocky (this is available on line) some copies handed out to the meeting . This report details the journey for carers and the cared for. Different groups and organisations are working towards improving the journey for carers and the cared for.</p>	RC

	<p>Work is on-going with CCGs around the importance of dementia care. RC then left the meeting</p>	
5	Update on the Care Act	
	<p>Feedback from EB As part of a bigger project work for the introduction of the Care Act April 2015 a specific piece of work was identified around meeting carers. The purposes of the meetings were to inform carers of the new Act and its implication for them.</p> <p>Methodology</p> <ol style="list-style-type: none"> 1. Establish contact with as many carers as possible across the county in the months of, October and November. 2. Also to look how we may start to “find” the 50,000 plus “lost” carers in the county as identified in the 2011 census. 3. Seek carer’s views around the information we currently provide, was it timely, relevant and appropriate etc. 4. Learn from carers around any preventive strategies that they are aware of, that has or is currently helping them provide care and any that can prevent the person they care for deteriorating further. Also “what do they know now” that would have been a great help to them at the beginning of their life as a carer <p>1. Establishing contact with as many carers as possible The first step was to contact and visit the four Carers’ Centres across the county. On visiting the centres we gathered information around which carers support groups they were aware of in their areas. Some of the groups the centres facilitated themselves. Other groups were either led by current or past carers or Voluntary agencies. Once we had that information, we then made contact with those groups to arrange to attend any schedule meetings. Also we did some investigation on the internet to identify specialist support groups to give us the opportunity to meet carers and cared for people with a variety of health issues e.g. Parkinson’s and MND, Out of this initial information we arranged to meet 16 groups 133 carers /cared for, county wide in around 6 weeks. With Ingelton being the most geographical remote location for a meeting.</p> <p>Face to Face Information meetings The meetings so far have been very informative; carers have welcomed us being there on the whole.</p> <ul style="list-style-type: none"> • At each meeting we use the same formula we run through a summary of the Act and its implications to carers .A copy of the summary sheet is given out at the end of the meeting • .Most carers we have met had not heard of the new 	EB and AH

Act,

- We explain about the changes in the Act relating to carers assessments based on recognised need ,the duty to create a healthy local, care market place , the need to supply more robust information around what is available in their local communities . If eligible the availability of a personal budget for a carer and what they would use one if they were eligible for one.
- We have spent time talking through prevention strategies and aids especially assistive technology. Most carers are not aware of theses aids that can help and support them.
- We also ask carers to tell us about any NYCC information leaflets they may have received directly from us or from other sources and were they helpful etc.

.Questionnaires

Also approximately 300 questionnaires have been sent out via the carer's resource centres across the country. 50 for the smaller centres Hambleton/ Richmondshire and Selby. 100 for the bigger ones Scarborough, Ryedale and Whitby. Harrogate and Carven .The questionnaires' have a copy of the summary sheet and some brief tick box questions around quality of information and prevention ideas.

2. Looking at how we may start to "find" the lost carers from the census.

- Most of the carers we have meet in these groups had stated they have not received a carers assessment (Which in turns means that they are not on the "system")
- During our visits to the CRC we became aware of the carers register that GP's use to hold (some still do) but the financial incentive for holding these registers has been dropped. I have emailed all our contacts in the CCGs asking them to highlight to the practices in their areas the importance of these registers in being aware of who is a carer and to sign post them to carers resource centres for support if willing.
- A number of people we have meet so far have been known to specialist health workers who have for whatever reason on the whole not sign posted carers to support services including carers' assessments.

3. Asking carers about the information we currently provide especially looking at its effectiveness and quality. Most of the carers we have met have stated that they don't remember seeing any information from NYCC .

Some carers have suggested developing a very short checklist that when you start supporting someone these are things that could help e.g. contact numbers for carers resource centres, what benefits are available, what benefits are means tested. Something that a carer can start using to

navigate their way around the various systems and organisations etc. One stop shop type of approach.

- We need to be aware it seems to be a "feast or a famine" sometimes we give out to many leaflets and people are overwhelmed and the essential information is lost to them and they just put them to one side .Or people end up with no information at all .

4. Asking carers around any preventive strategies they can think of that had or are helping them provide care and any that can prevent the person they care for deteriorating further

Discussions have taken place around

- Assistive Technology, but most carers are not aware of these services
- Direct payments, There is a similar response that people are not aware of these- are very valuable in looking at prevention as care packages can be much more flexible and person centred
- Carers Personal Budgets With the new act these will come into play and how can these be spent to improve the burden of care etc.

Areas of concerns/interest noted from meetings

.Information, need to look at when and how we deliver information and its quantity, relevance etc.

- number of carers in the groups have not received carers' assessment.
 - Benefit information this is not directly a HAS responsibility but we are very aware that this is an area that has a huge impact on carers , this appears very hit and miss with most finding out about benefits like the attendance allowance for example by word and mouth,
 - People being involved with specialist staff who do not seem to be sign posting carers for assessments and support
 - The professional carer slots 10mins or 15mins not working on the whole for carers or service users
 - Concerns about information going on line with the demographic of a large number of carers being elderly they are concern they will not be able to access information.
 - "Housewife stamp" wife pension linked to husband due to NI contribution this is lost to the wife if husband goes into full time care.
 - One Cares Centre reports 7 out of 10 referrals are around support for carers caring for someone with dementia.
 - Self-funders left with no support to access services also some reluctance around securing care and support due to the financial pay-out leaving the carers vulnerable to "burnout"
 - number of carers who have had carers assessments have not had regular follow up reviews these review are important if looking at prevention care packages breaking down.

	<p>Innovations Imaginative way to bring carers together book club run via a conference call.</p> <ul style="list-style-type: none"> • Imaginative way to bring support out into the communities e.g. pop up carers centre e.g. in garden centres, identifying carers champions in smaller communities. • Development of phone apps to help cares. <p>AH circulated information regarding eligibility criteria also examples of other authorities carers impact forms. Due to lack of time AH asked people to email her their comments</p>	
6	Any Other Business	
	<p>IP More thought needs to be given around Carers training for example manual handling .also managing challenging behaviour MS reported that his sons Community Nurse had given them good advice around coping with challenging behaviour .</p>	
7	Next meeting	
	Dates to be announced for 2015	AH