

## **GO CARER EVENT**

*A carer-run event was held at Hallmark Hotel on 25 October 2014. We ran sessions about relaxation, life-saving skills, new rights for carers and a free-flowing 'open' discussion. Throughout the event, we continuously asked carers about their views when thinking about re-shaping carers services in the future*

We asked 140 Derby city carers and their families:

- What type of service do you use and why? (p1)
- What future support services would you like? (p2-6)
- How do you want Derby city partners to implement the Care Act 2014 for carers? (p7)

We also asked:

- What have the costs and benefits of caring been? (see appendix 1, p8)

Thoughts by carers about the event and a self-evaluation by Creative Carers appears on pages 9-12.

*There was a lot of feedback. We have summarized it in themes rather than kept it verbatim so that it's easier to understand when you read it all at once.*

## **FEEDBACK FROM CARERS**

### **WHAT TYPE OF SERVICE IS USEFUL TO YOU AND WHY?**

*Carers use a diversity of carers support services. They have received support services in groups and individually. They have learned, and gain support from, other carers and those paid to support them.*

- Services which provide support and information to us in groups
- Thorough, knowledgeable and detailed advice given promptly at the right time
- Specialist sessions e.g. a session for carers about severe mental health conditions so that carers can ask for advice from someone who understands
- Preventative work e.g. a carers' group session about severe mental health needs
- Self-help and other support groups which exist for specific conditions – helps to develop knowledge and understanding
- Having an emergency plan in place, knowing there is 72 hours free care if something happens to me unexpectedly
- Make use of day centres door to door. Are very good and caring people
- Having information provided clearly and helpfully – this doesn't always happen
- Community support organisations – carers are everywhere
- Carers groups
- Specialist help around the mental health of people with alcohol problems
- Access to free training sessions

## **WHAT FUTURE SUPPORT WOULD YOU LIKE AND WHY?**

### **SOCIAL NEEDS**

*Carers would like social opportunities to spend time meeting new carers and ones they know already. They would also like opportunities for social occasions which they can share with the cared for – in recognition that it can often be very difficult to separate out the two sets of needs. The possibility of shared social events has more scope now with the Care Act 2014 coming into force. The needs of the cared for and carer are now both recognised. This might give rise to finding ways of supporting both sets of people in the same place (but perhaps in different spaces and coming together if/when appropriate)*

- Suitable service for both carer and caree to access together i.e. holiday/breaks
- More social events for carers to ward off depression etc.
- Inclusive events for all the cared for family – like a massive picnic
- A 'one-stop' shop specifically for carers where carers can receive advice, information and can also go regularly for carers' support
- Somewhere to go for an hour or two to 'switch off'
- More Carers groups
- Carers groups themselves need financial and other support
- More activities for disabled people – so that carers gets rest and disabled person feels valued by going to a group meeting with others etc.

### **EMOTIONAL NEEDS**

*Carers recognise the importance of emotional well-being. A lot of emphasis was placed on it during the event. The range of ways in which carers felt they could be supported, emotionally, was broad. It included individual support via a range of methods, group support and peer support*

- Increased formal psychological support
- Isolation is a big problem – need a dedicated phone line – out of hours with trained people. Just to talk, get comfort. Similar to Silverline and focusline – out of hours.
- Link to other carers – peer support for carers
- Counselling support services
- Support bereaved carers also
- Carers need 1 – 1 support – therapy. Help to adjust
- Peer Support
- Reduce Isolation
- More emotional Support
- More to boost self esteem
- Trauma – Cancer Carers need help
- "Emergency plan" gives many carers 'peace of mind'

## **INFORMATION, ADVICE AND SUPPORT**

*Carers recognised the importance of receiving the right information, promptly, at the right time. They want easy access to information. Carers want to receive a broad range of information from one place and also have alternative ways of finding out relevant information. For example, have an information pack but also access information online. Attendees felt that different groups of carers need different kinds of information*

- Information about carers groups and help given at the point of becoming identified as a probable carer (ie when cared for is first identified as having a problem) – including access to financial/benefits advice
- Self-help and other support groups which exist for specific conditions – helps to develop knowledge and understanding
- A 'one-stop' shop specifically for carers where carers can receive advice, information and can also go regularly for carers' support
- Link to other carers – peer support for carers
- Not everyone has internet or can readily access information so information needs to be provided in different ways
- Sometimes, information is provided by carers' support services in a limited way – carers need as much information as possible
- More carers support groups in Derby
- Carers need to feel confident that they are receiving up-to-date information promptly and accurately and know what to do and where to go to access it
- Younger carers need help, under 40's – separate group
- Help for teen carers – help in schools
- Care services should have a time-frame for when they get back to you and carers should know what it is
- We needed adult care from DCC
- Easy ways to navigate the system right at the beginning and/or help with navigating the system
- Information needed about carers' services in the city and information provided should be consistent so that it reaches as many people as possible
- Need help with forms, they're hard and they put you off accessing support
- Peer Support
- Information and advice with less red tape

## **PRACTICAL HELP**

*Carers recognised the importance of practical help in their lives. This is particularly so when it comes to activities for their loved one. They want those activities to be meaningful for the loved one, however.*

- Activities to free up carer
- Transport for disabled people
- Community bus needed
- Door to door bus – supermarkets and town trips, like there used to be, stopping these has isolated cared for more than ever.

## **HEALTH**

*Carers strongly recognised the important role health can play in giving carers support and connecting isolated carers with available support. They made the following suggestions about strengthening health's role identifying and supporting carers:*

- Doctors need a pack with ALL information in it so they recognise a carer when they encounter one
- There should be more information in hospitals about carer support
- Information for carers can be held at GP surgeries
- GP's should be paid to provide carers flu-jabs
- GP's actively finding 'hidden' carers
- Health of Carer – GP and Medics need to be aware of who a carer is and what their likely needs are
- Health of carers – Back problems, stress
- GP services need to recognise carers
- Consistency of service needed from GP's - some GP's need training, others are good
- Hospital Support – For cared for – need education, not just medication

## **GENERAL COMMUNICATION**

*Attendees felt that more could be done to improve ways of reaching carers in the city. They suggested:*

- Using Radio Derby/local media to list carers events
- Relevant groups need to be fully informed about carer service development
- Setting up a Derby carer's network forum on social media – Facebook etc. It would act as a support group for all carers to network online
- There needs to be a new drive to promote being a carer to wider society
- Better links between support services - bereaved carers need to be properly supported, for example

## **TRAINING AND GROUP SUPPORT SESSIONS**

*Carers want general training and support and also specific training about particular topics. They also want others, such as social workers, to have ongoing training about carers' needs*

- Mental health awareness event for carers
- Work-based 'awareness' sessions (i.e. employers/industry) to promote understanding of carers needs and PREVENTION
- Carers need education and training opportunities
- Groups of carers can help other carers' groups set up around the city
- Life Skills for adult children - autism
- Courses – need FREE courses to help us develop
- Social Workers need training – not always carer-friendly
- Some GP's need training, others are good

## **RESPITE**

*Carers want easy access to short-term respite and an easy system to use so that they get it. They want an extremely flexible short-term respite care system to meet their needs. They want joined up thinking – for example, pamper days or training where the needs of the cared for are adequately met at the same time. They also want affordable, long-term occasional respite*

- Increased respite care funding
- Easier access to sitting service for regular meetings e.g. 2 hours every 2 weeks
- Proper respite
- Respite support with funding to facilitate it for both the carer and the person cared for.
- Respite services need to have a clear communication process so that carers know when someone will get back to them
- Respite
- More Pamper days – We are better carers when we get a rest
- Respite needed at all times convenient to carer
- Need a flexible sitting service
- Sitting service – need to access in a quick and easy way

## **FINANCIAL WORRIES**

*Carers had a range of worries about finances. They mainly divide into worries about the finances of individual carers and worries about local funding for carers services and that of the cared for*

- Increase in allowance
- 'freebies' from firms so that it off-sets the cost of being a carer
- There will be no money to implement the act
- Services will become so means-tested that it won't be affordable or available
- Inadequately funded
- Need more funding
- People who have paid taxes all their working lives e.g. 40 years should be allowed care related support equal to their tax input
- Lack of Money
- Not enough money to fund such a wide ranging brief so definitions being limited to suit funding (refers to duties under the Care Act 2014)
- Carers should be allowed to earn more than £100 and claim carers allowance because £160 is not enough to live on
- Financial assessments needed to help with bills etc.
- Council and other cuts will impact on services provided
- Personal budgets are allocated and then taken away – these need to be consistent for carers to have improved quality of life
- Rules and Regulations cause financial worries – e.g. when carers' house is sold, not fair

## **NEW RIGHTS (IMPLEMENTING THE CARE ACT 2014) – CITY RESPONSE**

*Overall, carers were most concerned about ensuring effective systems are in place to cope with additional demands. They want easy access to assessments and services and no unnecessary delays*

- Strengthen existing services (give them more capacity, more scope, more resources)
- Carers will need extra advice and guidance about the assessment otherwise it will be used to take them out of services
- Being clear who does the assessments
- Delays in assessments may get worse if additional staff are not funded/trained
- Carers need to know and understand the process of assessments, including time-scales
- Need to make sure carers understand the act,
- Carers of disabled children and young carers are covered by two acts – how can the city make it as easy as possible for them to access services?
- Not all carers are retirement age and caring for elderly people. Younger carers should be recognised
- The new Care Act has some very level definitions which could be interpreted very differently by the various authorities
- I think the new definition provided for a ‘carer’ is offensive (i.e. ‘or intends to’). This is so broad and will therefore have an impact on services delivered!
- Is it well thought out? Will it penalise the carers e.g. Young carers, adequate information, how this is communicated, young carers should have a voice
- Unsure of what help is out there and if future cuts will be put in place
- Where do young carers fit into this act, whether they will be heard, they would need support in expressing their views and their rights need to be protected?
- Need organisations with adequate financial support for carers and the cared for e.g. Respite organised information/advice
- Social services workers should also be involved with carers for assessments so that the social/community life of the carers and the cared for have their needs met holistically
- DCC social workers – need to make consistent decisions, regardless of change in social worker and have an open and positive attitude towards carers
- New Care Act needs to be implemented properly – DCC needs to respect its existence and take its legal duties towards carers’ seriously
- It’s not helpful when workers change – need a consistent worker in the new system
- Assessments should be introduced to carers just after 3 months of caring achieved

## **APPENDIX ONE – DERBY CARERS' VOICES ABOUT CARING**

*Carers recognise that caring comes with rewards*

### **WHAT I APPRECIATE ABOUT CARING IS...**

- Enjoying time with person/mother care for
- Feeling useful/needed/wanted
- Appreciated
- Being involved as much as possible with relative's support medically, financially and physically with outings etc.
- Meeting like-minded people
- Feeling a job is well done
- Satisfaction with the care I provide

*They also recognise that caring can mean they lose out*

### **CARING HAS COST ME.....**

- Time
- Emotional stress
- Loss of earnings
- My role as a daughter has now become a 'carer'
- Too many hats!
- Strain on relationships
- Ability to be involved in organisations not related to caring
- Work promotion
- Career choices
- Career development at work – I no longer have time to pursue further study pathways
- Lack of sleep which affects decision-making every day
- Isolated/lonely
- Financially and brought on a home change permanently

## **APPENDIX TWO – FEEDBACK ABOUT GO CARER EVENT**

### **SELF-EVALUATION FROM GO CARERS:**

Overall we thought:

- We managed to attract a large number of carers and their families. Carers were diverse in terms of race, age, disability and gender.
- Our ethos of being carer-run, led and organised was understood and appreciated by carers and their families
- Having the cared for present was a support and help to many carers. At the same time, we provided optional separate space for the cared for.
- We provided for a diverse range of needs and tried to keep carers at the centre of all we did
- We kept to time whilst providing a range of interactive activities
- We managed to get the right balance of useful information with social, light-hearted entertainment
- We were right to actively engage carers groups in the event and support their income-generating activities – their talents were impressive

### **What we'll do differently next time:**

*We'd very much like to provide a similar event to carers again in the next 1-2 years. It's a way of carers valuing ourselves and each other by having a voice and receiving useful information while, at the same time, enjoying entertainment and each other's company*

Next time we will:

- Use more than one method of confirming places to all carers
- Have a bigger venue and invite more carers (we had a waiting list)
- The stalls run by carers groups were fantastic displays of creativity but we need to have them more visible rather than in an out-of-the-way room (the stalls were originally in the more visible Wyedale but a room change was requested of us later on by Hallmark due to the numbers we had and health and Safety reasons)
- Have information on the day about the aims of different sessions as well as send it out in advance
- Stick strictly to the number of spaces available for each session otherwise some sessions become too big with too many people in them

### **CARERS TOLD US:**

- They enjoyed the event
- They felt more relaxed after the event
- They felt more informed
- They enjoyed the new rights presentation
- They enjoyed meeting and chatting with each other and learning from each other
- They want more events like it

- They want to be involved next time and be given information about future Creative Carers events
- They received useful resources

## **THE DIFFERENCE THE SESSIONS MADE**

*We asked carers some questions at the end of each session to see whether we had made a difference*

## **NEW RIGHTS FOR CARERS**

*This session covered existing services for carers and how new rights will change the local landscape.*

100% of carers said that they felt more confident they could receive or access ongoing support if they needed to. 100% said they felt more confident that they know where to go to get help generally. 100% said they were sure they would use a new service for the first time. 100% said they were very satisfied or satisfied with the content and delivery of the training.

## **COMMENTS**

*I am not a carer but thought the session was very informative, presented in an interactive way and really helpful for carers.*

*Picked up lot more information.*

*To me, it's all about being aware of what support is there and how to get access to it so this day is really useful.*

*First time I have attended an event like this, useful contact. Thought provoking.*

*Looking at your training programme, I work p/t so courses in the evening would be good.*

*Very useful topics and excellent delivery*

*There is obviously much more help available than I was aware of. It needs to be much better publicised.*

*Good event, More!!!!*

*Very well presented, thorough and welcoming event. Much appreciated and lovely to know of imminent changes ahead. Well Done!*

*Very positive useful conference for information, up to date, and listening and sharing ideas with other carers.*

*I was so rocky when I arrived and now I feel better.*

*Great Day, can we have more of this kind of training and support.*

*Very good*

*I am cared for with schizophrenia and came along to support my carer, I really enjoyed the talk.*

## **OPEN DISCUSSION**

*This session focused on existing services and what kind of services carers would like in the future*

100% of carers said that they felt more confident they could receive or access ongoing support if they needed to. 94% said they felt more confident that they know where to go to get help generally (1 person said there was no change). 94% said they were sure they would use a new service for the first time (1 person said there was no change). 94% said they were satisfied with the content (one person was neutral) and 100% said they were satisfied or very satisfied with the delivery of the training.

## **COMMENTS**

*Very Informative*

*I have enjoyed the session, discussions were very interesting. I am more informed.*

*More information and support is needed to ensure carers identify their own needs.*

*It was valuable to give ideas on how services for carers can improve*

*Good to hear other points of view, very good discussion. A helpful day.*

*The meeting has made me realise there is a lot more help for me, and where to get in touch with associations to help.*

*Nice to hear others talk of their own personal experiences of being a carer*

*Good training*

## **RELAXATION**

*This session was about relaxation tips and techniques. It was about planning relaxation and discussing, and agreeing, how to relax well. Some carers had different expectations of the session and that affected their feedback. We have learned we need to reiterate the aims of the sessions when people sign up and, at the start of each session, so carers can check they have chosen the right session to meet their needs*

56% of carers attending were less stressed and anxious at the end of the session. 61% said they felt more confident that they would access or receive support for their caring role. 61% said they felt more 'empowered' (confident/ happy/satisfied) about their role as a carer. 88% said they felt either satisfied or very satisfied with both content and delivery of training (one person said neither). One person was not happy with the session and explained she felt it did not meet her expectations.

## **COMMENTS**

*Positive, fun sharing session*

*Great presentation/delivery of information with practical things you can do to help yourselves relax and focus on*

*Perhaps more relaxation techniques better than the time spent on bingo game*

*Big group for the size of room (Feedback from CC - Session should have only been for 20, but people went in this session when should have been at another)*

*Liz very good at explaining*

*Good session*

*Very important to give more sessions*

*I feel these events could be very valuable to carers to access more information, found the session very good, Liz is very informative.*

*Very good delivery, enjoyed it*

*Was hoping for guided relaxation activities*