WHAT DO CARERS LIVING IN DERBYSHIRE WANT?

A report based on feedback at a carer-led engagement event held at Chesterfield on 26 June 2019.
1. INTRODUCTION

1.1 Who we are
Creative Carers is a local organisation run BY carers FOR carers. We have been facilitating a range of carer-led activities for a number of years. We’ve also specialised in ensuring carers’ voices come together and a light is shone on our collective points/concerns. We’ve produced a range of reports following carers’ conversations including recommendations for change.

1.2 Carer-to-carer
Carers respond best to conversations where there is acknowledgement that carers have insight, experience and knowledge about health and social care systems because of our caring role.

1.3 About this report
This report pulls out key themes arising from an event held in Chesterfield at the University campus on 26 June 2019 with around 40 carers. It’s one of a number of similar reports being produced as part of a new project. We have obtained short-term funding for this project (called Strength-in-Numbers). The over-arching aim of the project is to find, and strengthen, a strong collective carers’ voice across Derby & Derbyshire which will help shape local current and future health and social care decisions. At the Chesterfield event, our intention was to ‘check-in’ with county carers to ensure that themes/concerns raised, yearly, haven’t changed.

Creative Carers have written a document called ‘What Carers Want’ which is based on conversations between carers dating back many years. What we say we want doesn’t change – with the exception, perhaps, of the expressions or language we use depending on the ever-moving health and social care landscape. The challenge is for decision-makers to really hear what is being said, understand its multiple benefits (to health and social care systems as well as carers and loved ones) and act to implement change. The next phase of the project is for the What Carers Want document to be implemented by a range of statutory agencies across Derby & Derbyshire so the document becomes embedded in their operational work.

2. FORMAT OF SESSIONS

The session used an “Appreciative Inquiry’ Model. The basic theory is that ‘society’ (networks in communities) evolves in whatever direction we ‘passionately, persistently and collectively ask questions about’ (Kessler, 2013, p1). The model draws on imagination and the potential to create possibilities for change. The session, therefore:

- Was only open to those with unpaid/family caring experiences (including any paid workers/professionals present).
- Focused on the future and time-travel – we imagined we were exploring carers’ support in five years’ time (2024).
- Examined what ‘excellent support’ looks like.
- Contained informal chats between carers and extended to email dialogues after the event – where particularly relevant these have been incorporated into the report.
• Included a ‘car park’ where all other issues were captured and could be responded to by decision-makers in different arenas at a later date.

(NOTE: The names of individuals or individual organisations referred to during the session have been anonymised. What we’re interested in is getting behind why an individual or an organisation has or has not delivered outstanding support so that lessons are learned for the future).

3. KEY THEMES

It was noted that, throughout the day, carers often used language spoken by local health and social care representatives. This impacted on the exercise about what is possible in the future. When health and social care professionals use jargon or particular words, they may be unconsciously limiting the future possibilities in relation to carers support. Despite this difficulty, a number of key themes emerged. They are themes which have been repeated over the years that we’ve been having conversations with other carers. They are set out below.

4. Peer Support

• There was an overwhelming wave of support for peer support activities and a better understanding about the skills and resources needed for this to be successful.

• “Peer support’ is more than ‘tea and sympathy’ (although a good cuppa can be great too!) - it’s about the sharing of information, skills, knowledge and supporting each other through particularly tough times.

• The right skills are needed to make peer support a success – it’s not about ‘worthy’ individuals or organisations doing it for carers but enabling carers to find ways that work for them and this includes proper resourcing of the work.

• The right funding mechanism is needed – blanketly using ‘procurement’ (dishing out large contracts to national or large local organisations) isn’t the best way of nurturing local community activities. There were concerns during informal chats that a ‘business approach’ has been adopted unquestioningly in Derby and Derbyshire when this is very removed from the diversity of local community needs. Carers consistently express a passion and desire for these community-based needs.

• It was recognised that ‘peer support’ doesn’t always work for everyone and that isolated carers who say they’re unable to ‘get out’ may need to be supported in a different way.

5. Taking Time out

• Carers repeatedly, across all the themes, referred to ‘taking time out’ of the every-day to look after their own health, wellbeing and simple daily needs (e.g. go shopping) or relax and/or socialise in peer support contexts with loved ones.
‘Respite’ was a word used on several occasions. We’ve interpreted that to mean either time for self to focus on ‘wellbeing’ or time away from the caring role – even if that means going out with the loved one for social or other activities. Many carers would have been unable to attend this event if they couldn’t also bring loved ones. Many carers are in symbiotic caring roles.

6. Co-ordination of support across health and social care

- Carers want processes and systems to be more straight-forward, less confusing and time-intensive.
- One key way they believe this could happen is by joining up the functions of health and social care better.
- They don’t want to keep repeating information or taking on the role of ‘information provider’ in case a professional may not have all the information about a loved one they need.
- Carers want to access the right kind of information and support immediately – they don’t want to be ‘sign-posted’ repeatedly.

7. Identification and support of new carers

- Existing carers recognise that, for newly identified carers, the whole process of support for self and loved one is overwhelming and confusing.
- Some believe that a ‘package’ of information for new carers would be useful.
- Others feel that meeting the right supportive person at the right time can help them identify as a carer and reach the immediate support and information they need quickly.

8. Out-of-hours support

- Carers consistently ask for 24/7 support because THEY are ‘working’ 24/7 and need access to support and information at all times.
- Carers have different ideas about how that should manifest itself e.g. a helpline, online support etc.
- It was recognised that many older people are unfamiliar with how technology can help with the caring role so technological solutions could be a barrier for that community of carers.
9. What does excellent support look like NOW?

- ‘A professional ‘gave me permission’ to move my dad from sheltered housing to a care home which helped me overcome my fears and guilt about making this decision’
- ‘Different practitioners within primary care brought it all together for us; the pharmacist, nurses, GP all came together and got us the appointments we needed.’
- Co-ordinated care really helped.
- The difference it makes when workers understand and go above and beyond their role.
- ‘I had a very good experience from community support workers who went above and beyond for us.’
- It helps when you get a particular person who understands.
- Good care management – continuity and understanding.
- Being treated respectfully on the phone.
- Being provided with respite help – but we have to ‘shout’ for help!
- Knowledge shared with other carers is invaluable.
- Example from a carer who used carer support in another county. I used a massage therapist who knew carers as individuals and picked up on previous issues discussed informally whilst providing periodic massages.
- ‘A particular speech and language therapist helped my mum to cope – equipment can help to a point but memory deterioration limits this.’
- ‘I received good bereavement support from the voluntary sector.’
- ‘We really benefitted from quick responses in a crisis arranged by Physio and District Nurses.’
- Carers’ peer support (e.g. art) group has been really helpful.
- ‘Time swap’ projects have good potential but benefits will only occur if more carers join.
- One good practitioner can really get the ball rolling.
- ‘We need a safety valve – we’ve faced so many fights just to get our daughter a basic service.’
- We want a centralised resource – a place to go.
- We benefit from ‘stressbuster’ sessions (sessions where we can focus on our wellbeing) and having someone there for the carer.
NOTE: Carers found it difficult to stay focused on ‘excellent support’ because the stories of their struggles seemed more overwhelming and dominant leading to a strong need to voice them.

10. What does excellent support look like in 2024?

- Resourced peer support in each geographical area
- There’ll be a 24hr support care line
- Carers will be properly trained throughout with free accessible courses
- People with animals will receive help if they have to go into respite or hospital
- All prescriptions of patients and health issues will be placed on all authority computers – combined so that all health people are informed of issues throughout the UK
- Carers will be listened to and their input will be valued.
- Carers will be involved in decision making in regard to the cared for person.
- Boundaries between authorities have been removed – hence no postcode lottery.
- ‘Officialdom’ will recognise, encourage, actively support and realistically finance peer support by and for carers
- Carers are supported through co-bots and/or assistive technology.
- Carers will be treated respectfully in all circumstances.
- We’ll receive wellbeing support (e.g. massages) which will come to us rather than expect us to travel to receive this support.
- Support will be combined – e.g. massage and emotional support so that both physical and emotional needs are considered at the same time
- There’ll be a mobile van with 2-3 staff. Inside will be a massage suite. The van will park outside our house, the paid care worker will replace the carer (s) within the house, and the carer receives a soothing treatment outside their home.
- Peer support groups will be properly resourced in 2024
- Carers will have regular breaks
- There’ll be a point of contact for new carers to provide information about support available.
- Even if equipment has been brought by the carers it will be supported by social services or their equivalent.
- Everyone should have a social worker if needed
- Entrance knowledge package for new carers
• Regular provision of respite care.
• Mental health support for carers.
• There’ll be more funding for carer social groups
• Financial support will include: Funding for ‘sitters’ so carer can actually work – there’ll be a legal duty for employers to provide this and the duty will be effectively enforced.
• In 2024, authorities will ensure carers are automatically given package of info/benefits.
• Benefit assessment sessions – people need to look at records and background and previous assessments.
• Access to free information, advice/training for older people who cannot use computers or mobile phones
• Should have a council point of call
• HMRC - if carer stops work this will automatically institute carers N.I credit to avoid loss of pension
• Person-centred for carer as well as cared for so carers needs don’t escalate
• A phone call will be received by the carer at least every 3 months (on top of any existing support accessed)
• There’ll be accountability amongst agencies to protect carers.
• *I would like to see more help for individual carers in the future and more understanding of the stress we go through on a daily basis.*
• “Regular’ and frequent stress buster groups will take place and ‘whole families’ will be involved.
• There’ll be more help filling in forms (because at present there is no provision on PIP forms for mental health problems). This causes more and more stress for carers and their loved ones.
• Practical, regular and timely help to be able to leave the house e.g. cover for medication, mealtimes etc.
• Quick responsive 24/7 help.
• Consistent quality and level of support across all conditions.
• To be listened to.
• Special housing for the patients leads to less isolation for carers
• One card for all shopping, bank and travel.
• Better health services; one point access for all
• Improving services by having regular meetings with the council
• No health discrimination
• Respite care
• Respite care will be appropriate to patient and carer needs. Important for carers to stay healthy and continue with caring role

11. How are carers supported in 2024?

• There will be far more assistive technology to do our tasks for us - Carer - bots!
• All forms of support will be to an excellent standard
• Training will be provided by a known named person
• Responses will be quick and helpful and 24/7
• Respite kicks in even if you are a self-funder
• Suitable respite from skilled expertise on all aspects of support including sight impairments, dementia care
• An abundance of respite
• Medication will be issued early on the day of discharge from hospital, everything will be in place before hospital discharge
• Inventive ways of providing respite
• People ring when they say they’re going to ring
• People will listen properly
• Carers will receive specialised support to navigate complex health and social care systems OR health and care systems are consciously and deliberately made simpler than in the present time.
• Joined up care/care in the community works well and is about community needs.
• We won’t have to be legal experts in health and social care because the systems will be simple and easy to understand – or there’ll be someone to help us navigate our way through them.
• The interpretation of the Care Act will be more inclusive to meet the needs of a range of disabled people
• Support line
• People will receive state help in a consistent way – it won’t be based on ‘post-code’ lottery.
• The workforce will have specialist training which enables them to support carers better.

• Carers will be supported to ensure systems, processes and services work FOR them, instead of against them. No longer will there be the ‘embattled carer’ syndrome.

• Funding will be appropriate and responsive to local community needs – the concept of ‘procurement’ and applying ‘big business’ principles to carers support will be obsolete by 2024.

• Carers will produce solutions to problems alongside decision-makers as ‘equal expert partners’, receiving appropriate support so that our strengths, skills and knowledge are used to the fullest possible extent.

• Health professionals will connect us to local community activities because they’ll know about them and their benefits versus medication.

12. How do carers support themselves in 2024?

• We’ll use a ‘time swap’ concept to support each other – providing practical and emotional support.

• We’ll carry on working in our communities providing support to each other – this will be resourced through the Care Act statutory provision.

• We’ll have good support networks that are easy to find and have a sense of belonging to the group.

• Diverse Peer support

• By giving ourselves some ‘time out’ FOR ourselves

• By finding the time to seek out the support

• Through good networks.

• Outings out – enjoyment days.

• More carer-led workshops for carers.

• By finding each other within society/communities and providing community support - this equals ‘peer support’

13. Who is leading the support? What makes them special inspirational?

• Leaders are carers and carers are leaders

• A prominent voice for carers i.e. a Cabinet Minister

• Responsive
• Reassuring
• Good co-ordinator
• Inspires confidence
• Not being let down
• Having empathy
• Health and social care in the community will be amalgamated as they do in Scotland so that leadership/decision-making is clear and easy to understand

14. What achievements made by Derby & Derbyshire carers in 2024 are you most proud of?

• Carers elected to high office
• Becoming decision makers
• Support networks
• Support networks operating in many different ways.
• Social, meetings, virtual, educational, professional support
• The resilience of carers e.g. finding informal ways of connecting with each other
• Peer Support groups are listened to by those who make the decisions
• We’ll have clear and easy access to the information/support we need at the right time and in the right place both for self and cared for
• Time swap concept to support each other – practical and emotional support
• Proud of carers as leaders who support other carers
• Proud of sessions like today which will be ongoing
• Good support networks that are easy to find, having a sense of belonging to the group
• Peer support
• Finding the time to seek out the support
• Good networks
15. The ‘Car Park’

Carers made the following varied remarks which were outside of our ‘time-machine’ imaginative exercise:

- When family members have to make key decisions, it is a struggle when loved ones are in denial. This makes it a challenge to get them through the process.

- It feels difficult taking over people’s lives.

- Carer for a totally blind person with other complex health requirements experienced ‘hit and miss’ support from Adult Care – some workers within DCC suggested raising a complaint and it took this to obtain a proper assessment. One worker was excellent and kept asking about carer’s experience.

- It is important to note that many of the positive experiences that carers have cited as helpful occurred out of the home – we must acknowledge the additional difficulties for those carers who just cannot get out of the home.

- It has been very difficult to get help, my husband relied on me feeding him every 2 hours. My only support amounted to 1/2hr per day. The timing of a further offer of help came all too late after he had died.

- What happens in the future all depends on the financial position

- Many of us really enjoy the local art group – set up by a local carer

- A good long marriage is the key to support!

- When people ask for help it should not be a lottery as to whether it is given or not.

- Since Derby City Council closed a carer-led resource at end Nov 2018 (on National Carers Rights Day!) I know of at least 3 carers treated for depression

- When will hospital staff talk to each other about a patient?

- When will staff listen to a carer?

- There is an unacceptable ‘merry-go-round’ that carers get entangled with – via hospital discharge, medication and hospital pharmacies. New medication is issued often without proper explanation and often the communication between hospital staff and hospital pharmacies goes wrong and we’re given the wrong medication for our loved ones.

- Delays in getting into support housing – it took 13 years to obtain suitable housing for our daughter.

- Need more training for the workforce – many do not have a basic understanding of caring.

- We need more understanding of what mental health carers go through

- Care planning is needed in plenty of time before hospital discharge
• While we are proud of what we choose to do and how those of us who can support each other, what we really need is central government to reverse the DWP culture of hostility towards disabled people especially re PIP/ESA and properly fund the NHS and social care so carer can spend their time caring not fighting battles to get appointments or services.

• Why does age affect the amount of money social services are willing to outlay i.e. privately purchased stair lift – now beyond economical repair – will social services provide replacement – no. At her age (98) we would probably take the view that she could live downstairs! – We do not have a downstairs bathroom – thanks SS

16. Conclusions

Carers:

• Consistently raise the same themes whenever they come together and often feel frustrated when they don’t perceive any change as a result – therefore, statutory agencies need to be explicit about how they will act on the common points raised at sessions where carers are invited to have their say.

• Are influenced by the language and jargon used within health and social care (e.g. at this event, the word ‘respite’ was used repeatedly) and that can have an impact on carers imagining, and articulating, a different, better, future.

• Were passionate, relaxed and comfortable being in a room talking to, and supporting, each other – it made a difference that the event was carer-led and facilitated.

17. Recommendations

Based on this event, our recommendations to our statutory colleagues are as follows:

• Produce a practical SMART (Specific, Measurable, Achievable, Realistic, Time-bound) action plan that addresses the themes carers consistently raise (many appear in this report) and which are captured, in very general terms, in the What Carers Want document

• Be honest and clear with carers about what can be achieved in 5 years, including any constraints

• Promote peer support by resourcing it and understanding that successful peer support requires community-based skills

• Consider different forms of funding which meets the needs of local communities – needs that include responsiveness, flexibility, carer-led activities, valuing and building on the strength of carers’ networks

• Resource carer-led participation in decision-making in ways that are meaningful, avoids tokenism, and the requirement for carers to sit in endless formal meetings – ensure that
skilled facilitators who can capture thoughts, opinions and decisions in different ways are involved in this participation work (known as 'co-production')

- Work with local universities and internal training programmes to ensure that specialist training around carers helps health and social care professionals to identify and support carers and connects carers to local community support, including carers networks

- Explore new ('plain and simple') language with carers that isn't reliant on health and social care jargon and frees up thinking about new possibilities for community and other support for carers

- Ensure that a range of methods are used to capture the diversity of carers and the diversity of their views on an ongoing basis (e.g. focus groups for carers whose voices are seldom heard by paying for transport/sitting costs and, perhaps, paying the carer for their time).

REFERENCES


Thank you

A BIG thank you to all the carers who shared their personal stories and opinions so freely and generously with us