

National Carers' Week
Carers' Celebration Tea - 12 June 2018
Event feedback



How did you find out where to go for carers support?

- Carers Trust – all information
- Social worker x3
- Care plan
- Hospital x4 (1x hospital social care team)
- GP (x4, 1x GP surgery contacted them to tell them, 1x Dr. organised social worker)
- Pharmacy
- Word of mouth (key) – x5
- LiON
- Carers Group x2 (1 in Clifton)
- Carers UK
- Carers Federation
- Jobs Fair
- Info on internet – not always easy to find
- Info from social workers is variable
- Went round the houses a lot, before the generic number was in place – this was years ago
- Could be promoted in ward newsletters x2 (Arrow too but costs).
- Hard to find central point of info
- You have to recognise that you're a carer, then be aware that you have rights, then find out what's available. It is hard.

Did you get help when you needed it? How did it help?

- Yes (x 4 – 'So far, so good!' 'Took time')
- Helped to know what's available
- Takes pressure off the carer
- Make time for myself (but caring responsibilities never leave you)
- Having more people involved in care
- Someone to talk to me about the cared-for person – decision-making
- School helped (Fernwood) – 1-2-1 support, good SENco
- Took a long time to get social worker (but that was a long time ago)
- Made parents feel better, not so alone
- Knowing who to contact for specific condition
- Wanted support re Direct Payments – carer support didn't know
- Not really, just given leaflets and 1 day gym pass
- No help from Paediatrics – asked to go to library
- No help from school at all
- Rainbows – Autism East Midlands supported parenting course

Most important thing carers support did for you?

- Someone to speak to
- Carer/staff knowledge
- Just getting help – introduced to Carers Hub
- Relieves stress on carers
- Some staff help
- Knowledge that there is someone there who understands
- Meet different people, different interests, activities
- Re-ablement team
- Counselling – telephone support
- Without the support I get now I couldn't continue long term. We get a night sitter 3x per week. I still wake up but I don't have to get up
- Community care officer explained to my mum the impact of caring on me
- First time in 3 years I've had someone to come in and help
- Falls and Bones team gave good support (practical, had time to talk, suggestions/medication)
- Someone there when my mum came out of hospital
- Respite
- Rapid response team
- Good monthly support
- Look after each other
- Alarm
- Surveys
- Massive support from City Hospital from Parkinsons project
- Dad gets help with garden, I don't have to do it now
- Found out things I didn't know today – given me hope that I can have some time to myself

Carers' breaks (respite) – how did it help?

- Really helped x2
- Carers Hub. 3x night visits
- Got respite hours from Carers Trust – really helped to go swimming and do stuff
- Visiting family, being normal, going shopping, me time, garden
- Having a lie-in!
- Joint activities
- Respite at weekends
- Holiday/see family
- Beneficial to get mum out of the house – she needed it. Long time to get mum into daycare.
- Organisation of treatment for family
- Family support with breaks
- Family arrangements
- Mutual carers – 1x stays, 1x holiday
- Can place cared-for person in a care home for a break
- Family/Carers Hub both pay
- Couldn't take up respite because couldn't leave mum. Too tired to take it all in!
- Difficult for person going into respite – they often don't want to go.
- Difficult to get residential place – lack of beds
- Have used before but it went wrong – need training and awareness of issues. Everyone is individual so need to meet them in advance to understand and plan care.
- Carers need a proper break
- 3x hours of respite through Carers Hub – but could it be stretched for more organisation/planning/groups/activities
- Yes but don't get support for a break – have to take the young person with them. No specialist can care like the carer.
- Can you trust respite care to do what they commit to do?
- Change could be considered a break, but is it a break?
- Difficulty of where to go and what to do. Sometimes falls through at the last minute.

Limitations

- General public awareness of carers – neighbour contact number for support/awareness, balance and trust
- Fear that respite is sustainable (funding)
- Cuts to services (personal care).
- Transport x2. Easylink is an option if you struggle.
- New to Carers Hub – just having assessments
- Make things easier – stop taking things away
- Need someone to talk to.
- Lack of/difficulty getting services (mental health) for cared-for person, puts pressure on the carer. Don't support carers at the expense of the cared-for person.
- Don't have a named point of contact
- Social worker on a case-by-case, not person-by-person basis – lack of continuity. Hard to have confidence in them.
- Have to find things out on own, have to fight
- QMC – acute support was appalling – intrusive, multiple – balance, help v.s privacy
- No support for carers of young people
- The future in general
- What else don't we know? (not everyone at the table knew everything)
- Assessments not taking account of social issues – loneliness/mental health needs – it's all about practical needs.
- Social workers don't understand the cared-for person's needs.
- No comms, handover/supervision
- Links w/other teams/services – blue badge, trams
- Funding – fight for it
- Mutual caring – support each other Link worker having enough experience to work with young person – not enough experience
- Sitting service – need more sitting service – should not be limited sessions.
- Agency via Council not good (timekeeping, unaware of when attending, need familiar face).
- Depends on management
- Issue re care support restructure (Jackdawe) – lack of communication between old service and new made carer feel worse!
- Support groups tend to be daytime – morning. Would help to have afternoon or evening sessions – but most carers are older.
- Time-consuming to complete activities/surveys/questions. Waiting for visits – burden.
- Asking same questions on many forms. Simplify process. x2
- Training for staff is too short.
- Lack of joined up thinking
- Complex/complicated to describe health issues
- Prescriptions x2
- Not always easy to access in emergency situation – more correspondence = more problems.
- Support to organise respite around the country