

Carers Rights Day 2017 Carer Workshop Feedback

Carers Rights Day is an annual event which raises awareness of the needs and rights of carers and makes carers aware of where they can get the help and support they are entitled too. This year's Carers Rights Day took place on Friday 24th November, with the theme, 'Make Connections, Get Support'.

Swindon Carers Centre held a Carers Rights Day event to bring carers and local organisations together. The Carers Choir welcomed guests to the day with a performance.

Speakers throughout the day included:

- A service development and organisational update about Swindon Carers Centre by CEO Susanna Jones and Deputy CEO Fiona Prinzi
- Sue Wald, Director of Adult Services at Swindon Borough Council
- Nicki Millen, Accountable Officer at Swindon Clinical Commissioning Group
- Robert Buckland MP and Justin Tomlinson MP



Speakers on Carers Rights Day 2017

Carers Strategy Workshop

Attendees also had the opportunity to participate in a workshop activity to ensure their voice influences the new Carers Strategy for Swindon. Carers were given two open-ended questions regarding their caring role to discuss on their tables.

Question 1: What are the key challenges in your caring role?

Question 2: What would help to make your caring role more manageable?

Answers given were qualitative and provide detailed accounts of individual experiences of having a caring responsibility and what it is like to be a carer in Swindon and opinions on the support available.



Carer attendees on Carers Rights Day 2017

The full answers given during the workshop can be found on the next few pages.

Feedback generated from this workshop activity will be used to influence the design of the new Carers Strategy for Swindon concerning the requirements of, processes and means of delivery.

Swindon Carers Centre would like to thank everybody who attended the Carers Rights Day event and to those who participated in the workshop activity; feedback provided is invaluable and gives professionals supporting carers in Swindon an insight into their caring roles and how better to support them.



What are the key challenges in your caring role?

- Change in providers and lack of specialist services
- Not experiencing early expert intervention and support for cared-for people with challenging behaviour relating to autism
- Carers are not experts in specialist support; are we doing more damage to the cared-for development?
- Lack of transitional support for young people with learning disabilities
- Planning between children to adult services should be smooth. Communication between services is making life a challenge for carers
- 'Plus Service' is time limited. Allowances stopped when in work; now we have to go back to the beginning to look for work. Cared-for on his own with no help and assessed as now capable of work
- Difficultly getting autism diagnosed. Marlborough House has gone and Chalsworth House has been taken over; but 1 year waiting list for diagnosis. Don't like giving the diagnosis and without the actual 'piece of paper', there is no extra help given in schools or for the family
- Different areas of the country offer different services for children. Seems to be more supportive in the North
- Not enough specialist schools for children with special needs and not allowed to go out of county for better help
- Meant to receive education until age 25, but no provision for this in Swindon. Uplands School is full and only takes children from Brimble Hill
- Maintaining independence and wellbeing (physical and mental health)
- Cared-for moving forward; job independence, support with work etc. After Plus, where does he go?
- I think that now I am on a pension, it is wrong that I am no longer allowed carers allowance
- Carers (paid for) are very short on time for their calls as the travelling time comes out of their client's time
- Speaking about a personal experience of two visits to GWH with my wife who has advanced dementia; she was admitted for bladder problems and on the first visit, the staff had little understanding of her mental state and her anxiety level was escalating as the procedure continued. This was even worse after the effects of the general anaesthetic wore off. On the second occasion, it was notably different. The staff could not have been more helpful, it was much less stressful. I would like to know what training is given to NHS hospital staff to deal with dementia
- Carers get no training, go around in circles to find support
- No money; lack of funding, lack of respite, lack of support
- Many carers cope but need more support on how to deal with problems
- Carers feel they are being judged as failing or feel embarrassed asking for help
- Carer not listened too; needs to be the expert
- Carers feel beholden to being in to receive cared-for back from day centre; this limits time they are out, putting stress on and can ruin time off. Can we have somewhere as an emergency drop off staffed by qualified people?
- We have had to teach ourselves how to cope with our daughter (our daughter doesn't appear to have any physical markers, her actions and behaviours are the only indicators of any problems) because of lack of support from social workers. Mainly because of the change, very often of

social workers, nothing is consistent, visits are timed and they don't get to know cared-for person or family

- Maintaining a happy disposition when internally, feeling mentally drained
- Anyone wishing to see cared-for person needs to make an appointment and not just turn up; prior liaison with the carer is important also. Failure to make appropriate liaison with carer can have traumatic knock-on effect
- 111 service lacking understanding and for me, failed to recognise that a carer has direct knowledge of cared-for person
- Ineffective communication between services and professionals – is there one clinical record? Information strategy to include those that are directly commissioned
- Ill for a couple of days so rang the number given on the emergency card scheme leaflet, and the first person spoke to didn't know anything about it. The two emergency contacts could not come (partners and relatives) so no help given; there needs to be a backup plan
- Doctor home visits work, but how can I fit in other appointments for myself (like the bank) if there are no carers (paid). Would I have to pay extra/agency would not accept a care change
- Coping with decreasing mobility
- Accessing medical help; are duo appointments available?
- Looking after my own health and wellbeing
- The Law! Rules and regulations
- Carers have no rights due to Mental Capacity Act
- Abuse of carers by the cared-for person
- Dealing with his mental health (learning difficulties) to enable him to understand his change in life (now 53) from a caring home to a nursing home; to be able to adapt and realise why and the wherefores of his incurable cancer
- Talking to dependents about their care in hospital when carer is not present; no memory to retain information
- System is not easy to navigate; difficulty obtaining assessments and being signposted to online forms
- Confusion over where to get a carers assessment
- Inconsistencies between adult carer and parent carer assessments and sharing assessments with other services
- GP surgeries covers register; what are the benefits as none really seen
- Ignored as a carer at the hospital; having to provide support for loved ones when no one is around and not offered tea/coffee etc.
- GWH tell you to go and see your doctor but no referral is made and they do not even record this. Big differences compared to Oxford hospital
- Challenging choices to go to different hospitals
- Complex cases when more than one caring role
- No open communication between adult and child social workers; not looked as a family as a whole
- Teachers are not suitably trained to support children with conditions e.g. ASD
- Several carers' children are not attending school as they are unable to attend due to insufficient support
- Postcode lottery e.g. social workers not standardised
- Abuse to carer mental health workers
- Lack of appointments with GP, despite being registered as a carer
- Own health and wellbeing

- Young adults being failed with the transition to adult services; we were just given a Lift Psychology Leaflet then moved on without the correct support or signposting into adult services and this impacts on health and wellbeing
- My son suffers a severe mental illness, one of the key challenges is during unpredictable events, especially when he is hospitalised and sent to a PICCI unit or acute ward some distance from home
- No support for cost of transport, train or petrol
- Sometimes accommodation nearby units/wards, sometimes not
- Early intervention are very good but are limited in what medication can be offered during a trauma
- Respite care the most challenging
- Difficult to know what support is out there
- Ensuring GPs are up to date with information

What would help to make your caring role more manageable?

- A care package that reflects my son's needs
- A more flexible approach to the use of that money
- A need for social outings in the budget (care package)
- A social worker who is allocated to us
- During hospital stays, need a better understanding of people with physical disabilities
- The whole system of carers visits needs a revolution!
- Better understanding with the hospital staff with people suffering with mental health. They need to be assessed as soon as possible to avoid their anxiety escalating and risking the involvement with police or any other services. When someone with mental health arrives in hospital, one of the first things they need is to find out when they had their last medication
- Male carers need support in caring, especially regarding personal care and their vulnerability
- More respite away from home for both cared-for and carer would be nice
- My own case, caring for a wife who spends most of her life in a wheelchair is hard to cope with, but I am assisted with four hours on Monday and Friday carers from Care Watch. Excellent care given which allows me the time to shop
- Training for all GWH staff on Emergency Card scheme, even if role does not directly relate to it
- The carer changed the time, organised through individual paid carer, this should be allowed
- I used to go to a Wednesday lunch at Lawns community centre. When they change the carer agency, they didn't consult me so the respite care did not include my Wednesday lunch. This is hopefully being sorted soon, however, I have missed three weeks. Timetable to be sent in advance and always consult carer if respite care hours are changing
- Training in dual diagnoses impact (learning disability and mental health)
- Early intervention support before it gets to crisis – crisis café?
- Agency/provision to help people with mental health get into work and find a purpose
- Support for the cared for if I am ill
- Form filling in
- Being listened too – carer is the expert and need chance to be heard
- A carers charter across all health providers and statutory services, job centres and council to be mindful employers
- Support finding respite care
- Residential short-term breaks
- Support from mental health practitioners
- Help with transition into care homes
- Work with SBC and Care Home Forum so that staff in care homes are trained in dealing with people with a learning disability
- Training for staff in nursing homes to talk and deal with people with learning disabilities
- Lack of facility for people with learning disability with terminal illness
- Feedback to NHS about gap in knowledge
- Lack of doctor appointments available – surgeries to have more of an awareness of patients with MS and long-standing illness
- Lack of respite care in Swindon; not enough facilities. Local authority could build residential homes, but local government block this as correct land and money needed
- Residential breaks – short term and longer term
- An appointed person to help navigate the system
- More support, communication and recognition for being a carer in hospital

- More physiotherapy support long term and short term when someone discharged from hospital instead of being left for the carer for long term
- More flexibility around PAs and what the care worker from an agency can do e.g. take dependant swimming or up to the shops
- More joined up working between professionals supporting someone with both mental and physical disabilities – need to work holistically
- Help with transition
- Planned respite breaks to enable carers to have a break – not enough facilities
- CCG and frontline services engaging in the community at a local level
- An expansive programme for early intervention with mental health after localities have funded their prison but does not appear to be funding for Swindon mental health!
- A strategy of carers role and life balance is important; all well supporting from 9am-5pm, but what about evenings and weekends
- What is being addressed with vulnerable young adults and cannabis life and taking medication?
- Is there a proactive approach for assessing time for supporting with self-medication and supporting them?
- Concessionary travel vouchers for public transport
- Peer support group
- Dial-a-ride days
- List of entertainers who don't cost a lot of money for carers breaks and activities
- Acknowledgment of the role of carers and their value to the community – focus on the positives of caring too