

Appendix 3: Neath Port Talbot Carers Partnership Event Feedback Report

Carers - Have Your Say

The Carers – Have Your Say event was held on Wednesday 27th September 2017 at The Centre, Baglan.

In attendance:

- 26 carers;
- Neath Port Talbot County Borough Council (NPT CBC) Carers Champion Cllr Richards;
- Principle Officers from NPT CBC Social Services and Commissioning;
- Staff and Trustees from NPT Carers Service (NPT CS);
- Abertawe Bro Morgannwg University Health Board (ABMU) Cluster Development Manager;
- ABMU Planning & Partnership Support Manager.

Three questions were used as a guide during the round table discussions. Carers had the opportunity to share their views and ideas throughout the morning. For those carers who did not feel comfortable speaking during the discussions they had the opportunity to write their views down.

Question 1

What is currently working well or has worked well to support you in your caring role?

There was an overwhelming positive response regarding activities and social groups. These included:

- Singing Groups;
- Arts & Crafts;
- Walks/Local Days Out;
- Health & Well Being Days;
- Information Sessions with Guest Speakers;
- Social Groups/Coffee Mornings.

Carers informed us that these types of breaks from caring are vital because:

- They feel supported and less isolated;
- Carers said that the support and understanding from others who are in similar situations is a great help with their caring role;
- The short breaks were seen as a lifeline.

The Carers Emergency Card was mentioned as a resource that is working well as is as the Carers Newsletter, produced and distributed by the Carers Service.

Carers found that information in the newsletter was very useful particularly for those Carers who were isolated at times and did not have access to the internet to find out about various services etc.

Newsletter information Carers found most useful:

- Fire Safety Checks;
- Health & Well Being Information;
- The Marketplace;
- Information on services from other organisations.

Other sources of support that is working well for carers are:

- Their Church;
- Pontardawe Library;
- Parent Carer Support Group that takes place in Bryncoch;
- The Carers Emergency Card was mentioned as a resource that is working well.

The availability of information in NPT Hospital has been very useful. A carer said ***“having information at the start of a caring role before discharge makes all the difference.”***

Carers Assessments were seen as a positive way for Carers to talk about their caring role:

- NPT Carers Service completing Carers Assessments was viewed as very positive. Carers said they felt more comfortable having the assessment carried out by someone other than Social Services;
- Having information needs met during the time of the assessment, Carers said was important & helpful.

Advice & Support with welfare benefits is important to carers:

- Carers said benefit support is vital;
- Carers said that being able to access the Carers Service for benefit support is “helpful as all support is one place”;
- Finance issues can be stressful and find it useful that the Carers Service can provide support with this.

Overall Carers felt the Carers Service is a great help and a good source of support for carers to feel less isolated.

Question 2

What services that are currently available, do you think need to improve and how?

All groups stated they would like more activities not only volume but also choice of activities. Suggestions were:

- To continue the singing group however have less of it so that more variety of other activities could be included;
- Increase information coffee mornings with more guest speakers;
- Include holistic therapies as regular activities;
- Carers said they would also like to see more walking trips and “round table talk”;
- Provide more health & wellbeing days.

Carers informed us that emotional support was important and suggested that:

- There was an out of hours telephone number to use, such as a carers hotline;
- A counselling service is provided that could be accessed when needed;
- More information to be included in the newsletter;
- Out of Hours support is important for the cared for as well as the carer.

A carer said that ***“being able to contact the Carers Service and say I just need you to listen. I don’t remember their names but I was in a complete crisis at the time and felt like I could breathe again after I finished speaking”***

Respite was recognised as being available, issues were raised:

- Although respite is available to some, carers feel there is not enough;
- There was a consistent response that respite needs to be available to all carers based on their individual circumstances and needs;
- Day services need to improve to give more choice;
- A sitting service needs to be made available Mental Health Carers;
- Carers would like regular provision of services for the cared for while the Carer attends activities.

In addition to the above, Carers gave a range of views and examples of how to improve:

- Carers Assessments - Call it something else, for example a Carers Support Assessment;
- Support on the telephone is important to Carers, particularly those who feel the need to “have a bit of an offload” or “just talk to someone who understands”. It

was also mentioned that this type of support is useful for those carers who find themselves more isolated than others;

- Take carers needs into consideration when assessing the cared for;
- Decrease the time the cared for needs to wait for services this could help the carer, less stress, anxiety and will be less chance of carer becoming unwell;
- Give Carers a package of their own, this could be everything from information, training to respite for them to have a break or tend to their own health;
- Support for Mental Health Carers. Why is it difficult for a MH Carer to access a Carers Assessment?
- Mental Health Carers also felt their own mental health needed to be supported;
- All groups said they would like improved planning for the future and in case a crisis was too happen. What happens if something happens to the carer? Although there is a Carer's Emergency Card and contingency planning on an assessment, Carers felt this could be improved and developed further;
- Carers would like to see more follow up after a carer's assessment;
- Transition from children's services to adult needed to be improved. Carers said this should take place at least one year before and there needed to be continuity to improve relationships.

There was a mixed response from Carers regarding their GP:

- GP Practices need to understand the Caring role and support carers more;
- Carers said that GP's are not interested, are not forthcoming with information on how to look after the person they care for;
- It means nothing to tell a GP you're a carer;
- The GP and the receptionist is very good and work around us;
- The GP Practice is very flexible and understands my daughter's needs;
- The GP's themselves do not understand or support carers;
- Carers also said there was unwillingness from hospital staff to discuss the medical case with carers and the family.

*A carer who had issues with hospital staff said **"How can people care if they don't know what they caring for?"***

Carers discussed a first point of contact and contact with Social Services:

- Carers said they were made to feel "grilled" when they contacted Gateway;
- Improvements needed to be made to the first point of contact;
- There was a lack of knowledge from Gateway and Social Workers regarding information of services available;
- It is difficult to contact the Social Worker;
- Carers said at times they felt left to their own devices due to not being able to access help from social services.

Overall Carers felt transport needed to be improved for the following reasons:

- To access their own appointments;
- To access the cared for appointments with the person they are looking after;
- To access activities, events etc that could provide vital information to their caring role;
- To enable them to have a break from caring and leave the house.

Question 3

What do you think is missing that would benefit carers? Think of a wish list and tell us what would make a carers life easier and make a difference. This could be anything...

- Regular, accessible and local social opportunities to meet with other carers;
- Events with guest speakers;
- Out of hours Information and support;
- Days out;
- Holistic Therapies, Tai Chi;
- A Carers Forum;
- Counselling services via GP & Third Sector;
- One to one support;
- Appropriate care packages for example longer calls and carers (paid) with life skills;
- Hospital Transport;
- Sitting Service;
- Localised Carer groups i.e. regular coffee mornings on rural areas;
- Regular First Aid and Manual Handling Training for Carers;
- A check-in service, someone to call and follow up if the carer requests it;
- Patient Experience groups at the GP Practices;
- More Respite;
- More Early Intervention;
- Respite for MH Carers;
- Improved NPT CBC Website for Carers;
- More joined up working with the Local Area Coordinators and the Carers Service;
- Improved facilities for Blue Badge Holders;
- Being made more aware of where to get information;
- More outdoor activities;
- Book Clubs;
- A "Calling Tree" where a carer can contact another carer;
- A willing donation box to be put out at every activity;
- More consideration and flexibility to be given to the carer and cared for at all health related appointments;
- A support group for carers to share their stories;
- Directory to put on the fridge;

- Support Services handbook;
- Improved transport;
- Flag systems identifying Carers at GP;
- Recognition.

The evaluation showed a unanimous response that this type of event should be held again. How often it should be held, ranged from monthly to annually.

Carers said they felt listened to on the day, and some carers commented:

- ***“it’s a wonderful way to air your issues you have as a carer with those that might be able to help”;***
- ***“Yes NPT CBC, NPT CS and the Health Board reps listened and fed back accordingly”;***
- ***“Yes today we spoke on the subject of mental health and I feel like I was heard”;***
- ***“Yes I think the people from the authorities listened to what we had to say”;***
- ***“Yes we were listened to closely and our views and comments were taken on board by all those concerned”.***