

**Carers' Involvement Forum  
February 2010**



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## Contents

Page 3	Introduction
Page 4	Table One: Carers will be treated with dignity and respect as expert care partners
Page 5	Table Two: Carers will have access to the services they need to support them in their caring role
Page 7	Table Three: Carers Will Be Able To Have A Life Of Their Own
Page 8	Table Four: Carers will not be forced into financial hardship by their caring role
Page 10	Table Five: Carers will be Supported to be Mentally and Physically Well.
Page 12	Individual Carer's View
Page 13	Evaluation of the Event

## Introduction

34 Carers from The Care Network and Rethink attended the Carers Involvement Forum in February 2010. Carers had been asked to come to identify what the local priorities are based on the national strategy. The day was introduced by Helen King, the Care Network's Carers Involvement Worker who explained the format of the day. Carers would spend the morning on a table which reflected one of the National Strategies priorities and identify which areas they felt were priorities in the local area.

Sonia Hutchison, the Care Network's Chief Executive spoke about the importance of carers views to let us know what we can do as carers organisations and to help us inform Bath & North East Somerset Council on what the areas carers want that we can't provide to ensure local carers have an influence on priorities for services. Carers were informed their views would influence the Care Networks' strategy and that the information would be given to the council to help inform the local carers strategy.

Although many carers arrived stressed from the pressures of their caring role, they worked extremely hard on the issues and had time to socialise over lunch and through art and leisure activities in the afternoon. As we said good bye to carers many said how much better they felt compared to when they arrived.

The opportunity was used to promote carers breaks and carers were encouraged to sign up to Give Us a Break to ensure they have ongoing breaks. Rosie Cole one of our carers spoke passionately about the importance of having a break and the importance of contacting Give Us a Break to take advantage of the wealth of opportunities available.

Mary Allen inspired carers by speaking about her upcoming Parachute Jump to raise money for The Care Network and her gratitude to the Give Us a Break project for providing her with a year's gym membership to get fit for the event.

The views of the carers are recorded by table and individually including feedback on the day itself.

## **Table One: Carers will be treated with dignity and respect as expert care partners**

### **TOP 6 Priorities:**

1. Carer's Assessments
2. Carer awareness training
3. Breaks, including access to emotional support and therapies
4. Equality of services, including health, respite, emergency planning and training
5. Having a voice and recognition of carers' roles
6. Information, including brokerage and advocacy

### **Discussion Notes:**

Day centres - hugely important having somewhere to go

Domiciliary care:

- must be reliable, at present too commercial and profit driven, places too much pressure on individual care workers
- Private care - can be cheaper and easier options sometimes
- Incidences where carer has to leave cared for person alone because worker didn't turn up as arranged.
- No continuity of care
- Setting rules with agencies, for example, no care worker is to come in blind

Taking Control:

- Screaming, shouting and threatening
- Being strong
- Demanding
  - All these get you what you want but the outcome is not always favourable. Eg. Demanding a carer's assessment but being told it is not relevant to a carer who works!

Too many carers at the end of their tether

- They don't have a voice
- Lack confidence to complain when services go wrong
- Don't have the strength or voice to demand better services
- Carers have a life too!
- Carers are forgotten about!
- "luck" on where quality services are available
- Privatised support services not policed
- Charities are excellent especially for caring in day centres
- Protection of vulnerable children must remain a statutory service role
- Clear accountability of services - who is chief boss?
- Bringing grass roots to top level services
- Young carers not given equal access to carers assessments

### **Additional comment provided:**

"Cannot stress how important it is for all professionals to listen to and involve carers in the support they provide and to work alongside carers to provide the right kind of support, particularly in mental health."

## **Table Two: Carers will have access to the services they need to support them in their caring role**

### **TOP 6 Priorities:**

1. Respite care
2. Personalisation
3. Information advice and guidance
4. Emergency support planning
5. Access to health and wellbeing services including specialist nurses and teams
6. Carer's assessments

### **Other relevant areas-**

Carer support groups, carer awareness training, residential care, fair charges, equality of access, money and benefits advice, annual health checks, carer involvement, understanding carer's needs from NHS professionals, recognition of carers

### **Discussion Notes:**

#### **Respite care**

- access to more respite opportunities
- more regular respite
- when the carer needs it rather than when available
- continuity of care
- emergency respite beds for mental health service users
- day care for dementia
- fair charging

#### **Personalisation**

- brokerage without cost

#### **Information advice and guidance**

- GP services as hub
- Dissemination to police, schools, community teams, groups, emergency services
- Central point of up to date information, not everyone has the internet
- Council news, council connect, local media, churches, British legion

#### **Emergency support planning**

- Formal service provided by the local authority
- Regularly updated
- Offered to all at time of initial assessment
- Not reliant solely on other family members

#### **Access to health and wellbeing services including specialist nurses and teams**

- Mental health
- Dementia
- Palliative care

- Drug and alcohol
- Access to police stations and places of safety
- Stroke
- Cancer and Macmillan
- Parkinson's
- Neurological disorders
- Good information

### **Carer's assessments**

- More available to more carers
- Regular reviews and reviews on demand Action plans that have meaning
- Are the right questions being asked

### **Other topics brought up**

- Challenging carers bills
- Carers register
- Emergency planning during recuperation as well as illness
- Continuity of care
- Mental health as well as physical health more holistic
- Poor referral by GPs to secondary services
- Different generational experience and expectation
- More flexibility in transition services
- Extra money to be given to existing carer services

## **Table Three: Carers Will Be Able To Have A Life Of Their Own**

### **TOP 6 Priorities:**

1. Respite care and occasional overnight
2. Information, Advice and Guidance plus Money and benefits and Peer Support
3. Equality of access to carer's services
4. Getting a break from caring
5. Housing support
6. Having a voice

### **Discussion Notes:**

- Starts with the GP or Consultant at Diagnosis - I & A on the range of services, or central point to access info.
- Needs to be a consistency of service across G.P's
- Hub for Information, Advice and Guidance where you can access FREE IAG on any relevant topic or be signposted to appropriate specialist area.
- Having a voice is paramount, but only if there is power to take action. Dispiriting and a waste of time if consulted and then no changes.
- Carers need to feel confident if they speak out action will be taken. A Carer's Champion with power is needed.
- A break for a carer needs respite.
- Options needed i.e - Carer coming into the home, respite etc
- Cost is a crucial factor
- Housing support essential for young cared for - to provide some independence from the carer and to give carers a break.
- Would require:
  - 24hour support from qualified staff
  - Assessment and support plan
  - Befriending system for cared for to help combat loneliness
  - Weekends at home
  - Support for carers to overcome feelings of guilt
  - Support from Carer Support Groups and Specialist Nurses (professional counselling not necessarily the best help)
- Respite is a key to ALL

## **Table Four: Carers will not be forced into financial hardship by their caring role**

### **TOP 6 Priorities:**

1. Money & benefits advice
2. Housing support
3. Information
4. Fair charges
5. Recognition of carers
6. Carers Assessments

PLUS the need for whole family support ie preventing family breakdown when there is a disabled child, leading to (usually mother) having to rely on benefits for income.

### **Discussion Notes:**

#### **Money Benefits Advice - How/who/why?**

- carers to be treated as equal partners by DWP/Tax office
- home visits by advice workers to help carers complete benefit forms
- health professionals (eg SWs) need to give accurate benefits advice at time of diagnosis
- dual-caring role should lead to increased benefit
- benefits advice should come from an independent source - statutory services may not be impartial
- unfair that mobility component missing from Attendance Allowance (exists in DLA) so discriminates against older people who become disabled

#### **Housing Support**

- need for more social housing for carers and disabled people
- affordable, accessible, secure tenancy housing needed for families with disabled children and people with disabilities - insecurity of private tenancies
- financial help needed with deposits which have to be paid with private tenancies

#### **Information**

- no jargon - simple to understand
- best delivered one-to-one, though phone, web and paper are all useful
- needs to be accurate and independent - carer needs to be confident the information-giver is properly trained
- should be timely eg before hospital discharge/at time of diagnosis/when situation changes

#### **Fair Charges**

- transparency - carers need to have charging clearly explained upfront, so they are fully aware of all the implications. Information may need to be written and time given to make decisions
- charging needs to be equitable according to income - unfair that those on a low income/no savings have to contribute a disproportionately larger share of their

income on goods and services - concessions need to be more available eg for breaks

### **Recognition of carers**

- carers views must be respected
- there needs to be greater media coverage of the role of carers and the problems they face to help to identify hidden carers
- CARERS ASSESSMENTS -
- **fundamental to all of the above** - SWs must actively promote Carers Assessments, and offer them to all carers. Without Carers Assessments, how will SWs know what carers want?
- Carers Assessments need to be reviewed regularly to keep up with changes in caring situation

NB Only 2 of the 6 carers had heard of Direct Payments, most expressed concern about having to 'find services' for the person they care for when they were already heavily involved in caring for them.

Carers Assessments - only 1 carer in a group of 6 has had a CA.

## **Table Five: Carers will be Supported to be Mentally and Physically Well.**

### **TOP 6 Priorities:**

(Some were 'doubled up' - and are in no particular order)

1. Brokerage - acting on behalf of carers + Information: ease of accessible info + Advice and guidance
2. Peer and community support e.g. carers support groups + Emotional support and counselling
3. Access to health and well-being services; GPs and specialist nurses
4. Getting a break from caring - leisure and learning activities + Respite care
5. Support for lifetime family carers (identified by one carer as being vitally important, "I will care for my son for throughout his lifetime - this is my life!")

### **Discussion Notes:**

- Better support from health professionals essential to improve care for carers and enable them to carry on caring
- NHS professionals need to be more aware of carers' issues and needs - they concentrate on the cared for person without recognising that carers have their own support needs.

### **Peer and community support e.g. carers support groups + Emotional support and counselling**

- Peer support invaluable - carers meeting together with other carers.
- Social interaction - reducing isolation - but not all carers want a group - sometimes male carers not interested in joining a support group
- Important to have professional emotional support and counselling services too, to support carer's emotional health & wellbeing.
- Support groups/counselling to be held locally across B&NES, not always in one centre.
- To be led by professional staff - carers don't have the time - or are too taken up with their caring role to set this up for themselves.

### **Getting a break from caring - leisure and learning activities + Respite care**

- Respite - knowing that there is respite available
- Knowing you can have respite when you want it, when you need it and for a reasonable period of time
- Getting a break is vital - but it's overcoming the challenges - leaving the cared for person behind, conquering the guilt factor!
- Finding out what's available in getting a break - often only find out by meeting up with other carers - 'word of mouth' better than leaflets...

### **Brokerage - acting on behalf of carers + Information: ease of accessible info + Advice and guidance**

- Brokerage - wording/terminology not easy to understand
- Would be best provided on behalf of carers by the Care Network as they are experts
- Needs to be centrally situated (Bath) with off-shoots/satellites in wider local communities across B&NES

- Needs to be an easily accessible venue - affordable - and with parking
- A 'one stop shop', first point of call for carers for all info relating to carers issues e.g. benefits, support etc.
- Centralisation of the brokerage service - important to have one focal point where carers can go to find out about everything that is available in B&NES without having to ring around and 'go round the houses'
- Needs to be independent from Local Authority- carers don't want to have to go to the Council or Social Services
- Acting on behalf of carers, providing support services and up-to date information, advice and guidance at times when carers want/need it

### **Individual Carer's View:**

Need Access to information - B&NES and Bristol do an audit of early intervention - know it's an issue from talking to others.

Personal experience - couldn't get access to any services for 5 year. Early intervention service has been fantastic since they became involved, they are trying to move back the eligibility criteria. It had been spiralling down hill situation for 5 years.

There is an increasing problem for rural GPs due to the relationship with drug abuse and psychosis and drug issues are becoming an increasing issue in rural areas.

2011-2015 - increasing problem

Better access to information in schools - someone to understand psychosis and sign post to early intervention, GPs, Police and community groups. Catching it early will prevent a lot of problems. All GPs in Bristol had information on psychosis so they could provide access to services. More could be achieved by following similar guidelines for dementia in other mental health areas.

Family time is the most useful thing with drug use:

Benefits

- Providing coping strategies to deal with violent behaviour
- Understanding of psychosis
- For the user - made him understand the impact on the family

CBT helped the user

Also really important that when the user moved to Worcester their was a really good hand over from B&NES

Hidden population of users - knows two families and they have no access to any carer services. The experience is that the son's condition determines their life style.

Carers need to know they can access carer support even if the user isn't accessing services. Free papers - Chew Valley Gazette etc. Could have more info in these papers - advertise by writing articles.

Need to reassure you it's ok to take a break.

Useful to have some success stories to encourage people to put them in a newsletter

Psychiatric doctor situation in B&NES is non existent - leads to long waits and lots of changes due to using students.

## Evaluation of the Event:

### Why you came today: what are your issues?

- Carers are being penalised for having saved £ in the past.
- Want to see better help for carers from the NHS & Social Services
- There is poor access to NHS dentists in B&NES
- Getting a break from caring
- To find out what help is available and to get a break
- Social reasons - to meet other carers and find out what others think of *Give Us A Break*
- to meet other carers
- because I suffer financial hardship and want to change things
- to find out what is out there
- to meet others
- to share experiences with others in the same boat

### 1. How far did the event meet with your expectations?

I came with an open mind and was glad I came. It was a very informative meeting. Good. More or less. Excellent. I was very impressed with info but would like one to one with something I need to know. 10 out of 10, full marks. Very well! I was very impressed by the carers round the table but was also concerned that none of them had been asked about having a carer's assessment in any positive way. Pretty well as expected and very good indeed. Thank you! Fully. More than! No expectations (not because I had a low opinion of the event, but because I was not as well prepared as I would like to have been. I thought it was excellent. It was what I expected. I found the meeting very helpful and enjoyed it very much. PS thank you so much for the wonderful meal! Was not sure what to expect - the event was VERY beneficial and alerted us to "Give Us a Break!" and it's potential. Very well. Completely, with many thanks to Andrew. Partially. Good. Ample time in groups to discuss particular aspects of the proposed strategy. Very informative.

### 2. Which Aspects of the events did you find most and least helpful?

It felt good to be in contact with other carers, having just become one myself. I found being able to talk with other carers very helpful. Speaking out and writing down the important points for each person. Meeting and listening to fellow carers' needs. Division in the tables for discussion - I think if time had permitted, discussions could have been concluded. Financial. Good interaction with other carers. Gaining a sense of realism. Alison's advice about community care assessments. Excellent discussion and would have been even better with a slightly shorter introduction. Services. It was a well covered event - 100% enjoyable well done Helen! Least helpful - not having enough time for the workshop discussions - Most helpful - was having some prepared options to focus our discussions. Sorting out people's priorities - interesting to find out other people's perspectives. Most helpful - explanation of Give Us a Break! - Least- the activities after lunch. Picked up useful information - not had time to follow up other points as some strategies interlocked. All the input on Table 2. Listening to others' perspectives was really useful - the activities were the least useful. Group discussions very helpful - rather

lengthy introduction to topics for discussion which were already written down in front of us. Talking to other carers who understand the problems best. Today's meeting has been beneficial and it has been good to talk it through.

### **3. How much opportunity were you given to discuss your main concerns?**

Enough. Quite a lot, but more time would have been nice. Half to medium. Every opportunity. Would have liked half-hour general forum for questions. Was busy getting sponsors. As fully as possible, given time allowed. As much as I needed there was no hurry at all. Could have done with more time for this phase of the event - there were many sensible comments made, which merited more time to consider than was available. Nearly enough time! Plenty! As much as needed. Time constraints were tight also didn't feel it was right to make an intervention on every subject - finally a lot of my "main concerns" are to do with my individual caring role but we were trying to make general points, so not appropriate to refer to own situation. I had plenty of opportunity to talk both one to one and in the group. Thank you - time went so fast! Plenty of opportunity not only during "table discussion" but privately. Good opportunity. Every opportunity. There was too little time to discuss the wide spectrum of carers needs - someone looking after an elderly relative has different needs than a carer of a young adult. Ample time. Time was very short for discussing other concerns. Satisfactory.

### **4. What Areas would you like to cover in Future Carers Involvement Forums?**

More specific information on what benefits can be claimed. Further discussions on subjects covered in today's event. More reasonable assessment of carers' finances, with regard to those of us who have been more prudent with their finances. More money to go to carers services like Rethink and Care Network than spending money somewhere else. More on specific topics with all carers who attend being able to voice their own views. Furthering the voice of carers with professionals. Money for carers and debts. Same as today as it is an ongoing issue under constant review. General information about all aspects about caring help availability - I know a lot of it has already been covered but recapping is always useful. Possibly the various assortment of conditions we represent in those we care for - some of our concerns are not well related to each others. All covered. All that we discussed - how have we advanced and have we progressed? How to increase membership and how to find and present evidence of unmet needs. It was all covered - I give you a gold star! Financial - if need help - set up easy access to where to go and what to do. Complete care for carers with all the necessary cooperation from hospitals, social service, GPs and community nurses. Access to services in the mental health area and provision of info. Promotion of early intervention - mental health. Carers Assessments. Areas where carers need outside services to help them to help them in their caring role and the standards of these services. Any further get together is a good thing as there are things we can all learn. Covered everything I could possibly want to know. Have learnt a lot. I feel very grateful to belong to the Care Network - many Thanks! Can I suggest a follow up meeting to discuss the various suggestions?