



Wolverhampton Carer Forums Information sharing surgeries - 22nd February 2011

Summary of Carer Feedback

Q1. Where do you go for information? / Can you suggest new ways of sharing information?

- Newsletter – need evaluation of content and methods of delivery
 - Frequency how often?
 - Delivery – paper version or email
- Health Services – Health centre, GP's, use of Information Boards, Hospital Discharge Letter, Expert Patient Programme (EPP)
- Professionals – Nursing staff, Social Workers, Carer Support Team, Personal Advisory (Connexions), Health Visitor, Patient Advice and Liaison Service PAL'S (based in hospitals)
- Internet – Department of Health, Department of Work and Pensions (Please add to this list to help us create a list of useful websites)
- Other organisations – some condition specific – MENCAP, Autism West Midlands, CAB
- Significant others – MP's, local councillors
- Help Lines (Which ones are the most useful?)
- Churches and faith groups – some existing (Can we make a list and describe the help available?)
- Retail outlets – Supermarkets, Train Stations, Pharmacy, Gyms, Early Learning Centre
- GEM Centre (Joint PCT and Wolverhampton City Council)
http://www.wolverhamptonhealth.nhs.uk/Services/Service_pages/Gem_a-z.asp
- Peoples Parliament (specifically for LDD)

Q2. How can new carers be found and encouraged to attend the forum?

- New ideas Wolverhampton Carer Focus Groups
- Newsletter – Format
 - Hot news by text
 - Changes in Legislation e.g. Benefits
- GP – One Stop Shop
- Conferences / Workshops – Local and National
- Specific ideas focussed
 - Changes to legislation / benefits
- Faith Groups in Churches, Temples

- Supermarkets / Shopping Centres / Train Station, Bus Station / Mini Health Centres
- Need for independent advocacy service (Is advocacy currently available in Wolverhampton?)
- Early Learning Centre (local)
- Gym – Notice Board
- Target employers / Sign post
- Improve carer recognition (How do we achieve this?)

Areas for improvement

Further develop information giving:

- In schools, colleges, (specials or mainstream), GP surgeries / Supermarkets / surveys and questionnaires
- Professionals need to be aware of what is available
- City Show forum – have a carers stand
- Adverts in the local press
- Parent Partnership
- Specific professionals by transition workers

Suggested ideas to send out information:

- In benefit letter
- Post Offices
- News – Press
- Using the media
- Local radio
- Need to be clear what support is / could be available to carers so that they can attend forum meetings
- Offer specific things to carers i.e. training, expenses, social activities (lunch clubs)
- Hold meetings in accessible places, e.g. schools, colleges and day care centres
- Trying to join up databases amongst different organisations involved in supporting carers. Little connectivity at the moment – keep separate databases of carers
- Need to have clarity about the role of the forum(s) (aims, objectives and Terms of Reference)
- Need to be clear about the role of forum participants (what is expected of them , what it can't be) Agree clear role descriptions of participants
- Need to know what outcomes are to be achieved and then publicise these to encourage more people to attend
- Need to have regular meetings
- Carers are keen to share information with each other in a systematic way (Are carers willing to give permission to share names, contact details etc?)

Q3. What do you think the priorities of the Forum should be?

- 1) To represent carers, voice a range of views and to be fully heard and listened to
- 2) To represent the views of all carers, especially carers that are currently being neglected e.g. mental health and people with Alzheimer's
- 3) To be a pressure group to get things done and hold organisations to account for their practices - not listening, not fulfilling their promises

e.g. improve communications between hospitals and GPs;

- it is vital that the carer is included in discussions about treatment and on-going care needs of the patient
 - If the carer is unwell and needing treatment, GP's and hospital health professionals must share information about the complications that will need to be taken into account to ensure the person being cared for is safe etc whilst the carer is receiving treatment and care.
- 4) Ensure that new carers know where to go for help Look at introducing a 'buddy system' to help each other at key stages e.g. periods of transition; carers want support for the people they care for to be better prepared, and in good time, for dealing with changes in provision of health and social care, at times of transition - especially people with Learning Disability: teenagers at about 13/14 years and those approaching retirement age.
 - 5) Improve communication between other support groups, to share successes and failures (not working)
 - 6) To be recognised as 'experts' and to train professionals on the role of carers
 - 7) To ensure that the needs of carers are identified and recognised and actioned e.g. their own health needs – the quicker the carer gets cared for, the quicker the person they care for gets looked after e.g. emergency hospitalisation for carer / community support
 - 8) To provide an advocacy role for carers
 - 9) To recognise the role of young carers

To look at creative ways of extending carer involvement (various levels) e.g. armchair involvement, attending meetings – (ladder of participation and consultation) voice of carers listened to and heard.

Impacts of a carer being involved in forums / meetings needs to be evidenced and shared to encourage new members and show something for their contribution.