



December 2003

REPORT CONCERNING

**THE
CARERS
CONSULTATION
DAY**

24 October 2003



Carers Together
A consortium of carers in Hampshire

Charity Number 1051879

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INTRODUCTION

The Carers Consultation Event was planned by Carers Together as part of its commitment to provide information and undertake regular consultation with carers in Hampshire. All known carers, organisations and groups in Hampshire that support carers were invited. There was a range of information material available and the day was enlivened by the launch of 'The Selfish Pig's Guide to Caring' by Hugh Marriott.

Prior to the Consultation, Carers Together had been hearing and recording comments made by carers from Hampshire, Portsmouth and Southampton. Many of these were linked by common themes but had been made by individuals in different places and at different times. One of the aims of the consultation was to find out if any issues raised during the day could be linked with those made prior to the day, and to identify those that should be followed up, with a view to developing a more flexible and responsive range of facilities for carers and ensure consultation followed carers thinking.

AIMS OF THE CONSULTATION

The consultation had two main themes and the aims were:

1 Carers Support Services

- a) To provide an opportunity for carers to:
 - i Give their views and identify their expressed needs
 - ii Identify current issues for carers in their locality
 - iii Identify areas of individual concern to them
 - iv Suggest areas for change or improvement
- b) To make carers aware of the range of services, support and information available to assist and support them
- c) To bring people together to share positive and negative areas of carer support so that issues common to several people could be identified and used to promote appropriate action to meet gaps between identified needs and services available.
- d) To monitor services already available, identify ways of improving services and promote the development of additional appropriate services to meet expressed needs

2 How Carers want to be consulted

- a) To discuss ways carers would like to be included and consulted
- b) Respond to the Government consultation 'Choice Responsiveness and Equity'.

RATIONALE

The day was planned to ensure that carers and older people were enabled and empowered to:

- Talk with others in the same situation
- Discuss their concerns and comments freely
- Share the needs they identify for themselves
- Have the opportunity to suggest possible solutions and share them with others

The essential components of the day were:

- To listen without imposing ideas or suggesting what carers might like
- To hear what they were saying in a friendly, comfortable, relaxed atmosphere
- To give carers of any age an opportunity to be respected for their wide experience, skills and knowledge
- To ensure people are able to make realistic and real choices

ORGANISATION OF THE DAY

The day was divided into 3 main components:

- Two workshops each with a different theme
- Annual General Meeting of Carers Together with the launch of Hugh Marriott's book
- Refreshments including lunch were provided throughout the day and were free

An essential part of the day was to give participants time to gather information and to mix informally with each other over a relaxed lunch. This interaction with ample opportunity for socialising and informal discussion and choice was deemed an important part of the day.

Interesting and essential activities included:

- The Annual General Meeting which gave all present an opportunity to vote for their representatives and find out more about Carers Together
- The launch of Hugh Marriott's book 'The Selfish Pigs Guide to Caring' and his presentation which was an interesting part of the day's experience
- There were members of Carers Together staff and volunteers available to assist with queries and to talk with participants
- As the focus of the consultation was to hear what people wanted to say, there were no formal presentations before the workshops

ATTENDANCE

A total of 70 attended the day. Over 40 were carers or former carers. Others included volunteers, representatives from Hampshire County Council Social Services, New Forest District Council and DWP Pension Service, a range of voluntary organisations in the county, and Carers Workers. In addition some people sent in comments and there was feedback on the day.

CATERING

Lunch was provided and all food and refreshments throughout the day were free. All feedback said the catering was excellent.

WORKSHOPS

There were two workshops each with a different theme. Carers and representatives from a number of voluntary and statutory organisations attended each workshop. The workshops were designed to listen to opinions, ideas and suggestions from the people present.

Workshop 1 - Carers Support Services (Appendix 1)

By Carers Support Services we included any service that helps a carer continue to care – not just those which are labelled ‘Carers Support Service’. The workshops were developed under headings - negatives, positives and constructive suggestions for change or improvement. It was an opportunity for carers to express or talk about their experience as a carer or individual in hospital, discharge from hospitals, community care packages, sitting services, day services, respite – including flexible response to their individual need, residential homes, how to get support, how to get information, what information they needed, what has worked for them and what hasn’t.

Workshop 2 - How do carers want to be consulted? (Appendix 2)

How do carers want to be included in consultation on, and development of, public services? How do carers want to be represented? What would help carers to take a more active part?

Consultation with carers is not always easy because they can’t always get to meetings, the timescale for consultation is often unrealistic, the timing of meetings is often not convenient for carers, the telephone is not the best consultation method and many people do not have access to a computer. Yet carers need to have a say at all levels of development, implementation and monitoring of services for them and the people they care for. All carers are different and therefore need to be consulted on an individual basis or on a particular service that they have used.

This workshop discussed the way carers can be included in consultation with statutory services including education, health, housing, social services and with voluntary organisations which provide services for carers.

Choice Responsiveness and Equity

There was an opportunity to look at, and for participants to provide feedback for, an NHS and Social Care Consultation taking place at the time called ‘Choice Responsiveness and Equity’. Over 50 completed responses were sent to the Department of Health as a result.

KEY ISSUES IDENTIFIED

Assessments

Carers do not feel that assessments are either offered or provided to them equitably across the county. They are not always offered an assessment and when an assessment takes place it is often incomplete or the carer is neither given the opportunity to change it or sign it as agreed. Many times carers are ignored in the assessment of care for their relative until professionals have made their decisions, but the carer is then expected to agree and act upon it without question. Carers need choice and to feel valued. Unidentified carers who are self-funding slip through the support network even though they are legally entitled to assessment and support in accessing services.

Communication

Communication with carers is often sporadic and uninformed and if they do not know the correct questions to ask they do not get the answers. They are often the last person to be informed of proposed actions but are made to feel guilty if they do not respond in the 'right' way. Most carers feel that communication with them only takes place when they pressure for it or when they are needed to agree the action proposed. Lack of communication between professionals from different disciplines and agencies, as well as with carers was felt to be a negative factor leading to duplication of effort and lack of coordinated action with best use of resources.

Consultation

Carers want to feel that they are being listened to, to feel valued and appreciated. They need to have travel expenses and alternative care costs paid promptly. Statutory and voluntary organisations need to take account of the needs of carers when planning meetings e.g. child minding is usually split into morning and afternoon sessions so a day meeting may need two sessions paid for; some carers cannot leave until the paid carer has completed their work and the sitter arrived so early morning starts are difficult especially if it involves travelling to the meeting; day centres and schools finish in mid afternoon so late meetings can also be difficult. The range of carers being consulted may need to determine the times of the meetings.

Consultation should be open, inclusive, informed, available, accessible, broad based, ensure feedback and action is reported back, not by paid individual carers, be time positive and realistic.

Any proposed action should be open to consultation prior to being implemented and it should not be assumed that carers want to be represented by an individual carer consultant who may have a vested interest or conflict of interest.

Positive feedback on events such as the Information and Consultation Day in Southern Test Valley in early October, providers and professionals 'hearing' the results and taking action as a result, and making consultation into a positive experience can enhance services, and support statutory and voluntary organisations in implementing needed and cost effective solutions.

Further Consultation Days should take place to review action taken and determine new priorities for future action.

Direct Payments

Most people agree that this is an excellent scheme that offers choice and flexibility. Some had not been given the opportunity to access independent advice from the independent Direct Payments Advisory Team at Carers Together and there was some concern about lack of people to employ in some parts of the county. Disparity in availability and choice for Direct Payments became clear during the discussion and the need for independent support and advocacy was highlighted.

Health and Social Services

There was felt to be a lack of real communication between health professionals and social service staff at grass roots level and that this lack of communication was also felt by clients and carers who often felt that communication with them was limited to being told what was being recommended rather than being included in the planning and implementation of a whole team solution. Many carers find that they are often the last to know when any decisions or actions are being implemented and they are expected to do what the professionals are saying without having a say in the process.

Hospital Discharge

Discharge from hospitals both in patient and day surgery was the cause of much concern. Carers being the last to be told anything prior to discharge, information provided too late, no care arranged on discharge, pressure from hospitals to take relatives home without support over holiday periods, difficulty in accessing social workers, no assessment of need, no choice in decisions were all quoted as problems by carers. Many felt browbeaten by professionals and would welcome some support during periods of stress and change in particular. Rapid Response teams when available helped.

Information

Carers need to be informed about all services statutory and voluntary available to them in their area and services that can be made available on request. This information is better disseminated by an independent organisation that is able to give unbiased and broad based information, rather than concentrating on the services that groups and organisations happen to have available themselves. New carers need to be aware of the range of services and support that can be accessed and this information is often difficult to find. There was appreciation for the Carers Together Newsletter 'Do You Care'.

Respite

There was a feeling that more carers are getting less time and that respite tends to be service related rather than flexible and innovative to meet individual needs. There is perceived lack of resources and little understanding of carers needs. There is little or no night sitting; two hours to 'enjoy yourself' when you have no transport is inadequate; lack of choice of day care; reducing care packages that do not give carers what they want or need; paid carers who are not allowed to do the job needed; paid carers who arrive late and leave early to get to the next client; insufficient time allotted for them to do the job; limited respite care beds; services are reactive rather than proactive. Parent carers feel particularly unsupported in respite.

Support

Support was felt to be inequitable across the county, although it was felt that in the interests of flexibility and innovation it was inevitable that some areas developed differently to others. There was however an inequitable distribution of financial support from statutory organisations, which meant that some areas were better off than others.

Preventative care was felt to be an important aspect of support. Development of preventative services would reduce stress and in the long term reduce expenditure on Health and Social Services, which tend to deal with crisis support.

There is perceived lack of support from services that are appear under resourced – insufficient OT time, insufficient Physiotherapy except in trauma cases, lack of access to Speech and Language Therapists or Dieticians that may be able to help with recovery and rehabilitation.

Some carers felt that mutual support networks helped but many carers felt the need to offload their concerns to an independent non judgemental person who would be available when they wanted them was a key to managing. They also felt that having an advocate to support them would be helpful when dealing with officialdom.

Summary

Feedback has suggested that the opportunity to be consulted was appreciated by all carers present and there were requests to be included in consultation on other topics that may affect them. There was concern expressed that the trend towards statutory authorities employing individual carer consultants would prevent carers being able to influence policies and provision of services through being consulted and being listened to widely and openly.

The numbers attending the day giving their experiences and opinions confirmed many of the negative points and issues raised prior to the consultation, but the real benefit came in listening to the good points and the positive suggestions for improvement, many of which will not cost more money but require a rethink about the way some things are done.

Comments on the day include

- Appreciated the opportunity to take part
- Enjoyed hearing that others had received similar experiences
- Really good to find out more about the services available
- Hearing what some people were saying was difficult
- Parking was a bit difficult
- The lunch was excellent
- I enjoyed the opportunity to chat informally with other carers
- Would have liked a loop system to be available
- The launch of the book was very interesting and encouraging
- Can we have more events that allow us to have a say in what we need
- Felt encouraged to speak and take part
- Glad I could take part in the government consultation – had not heard about it before

OUTCOMES AND FUTURE ACTION

Assessments

Carers were able to identify that, when they had been part of a positive assessment process that had been undertaken together with a professional rather than by a professional, the results was more supportive and generally better received. It was felt that more training of professionals in getting alongside carers and seeking innovative solutions may be of long term benefit as well as making better use of limited resources. Action is being taken to improve the independent information available and to make it more widely available. There is a need for short-term advocacy to assist carers through the assessment process and give them support.

Communication

Communication should be a two way process and many carers have a better idea of the solution to their needs than professionals and is very often a cheaper or more cost effective method. Increasing the ways for carers to communicate their needs and ideas, access information as well as to off load their stresses is one of the ways of moving forward. Many carers have stated that they would prefer this to be an independent service that allows them to talk freely and know that it will not affect or penalise the person they are caring for or their own support needs. There is an opportunity to investigate this as part of the Carers Support Service and Information Resource.

Consultation

All points from the consultation will be fed back to the relevant Health and Social Service teams and organizations. In view of the need to ensure that carers are included in the planning and implementation of services, suggestions will be made that consultation events run on similar lines to this one to allow carers to input into service provision and development. The cost would be no more than and probably less than the cost of paying proposed carer consultants. The result would be a comprehensive consultation exercise, the result of which would have real validity.

Direct Payments

Every carer is entitled to independent advice about Direct Payments and help and support to set it up and manage the scheme. This independent support is available from Carers Together but it appears that many social workers and care managers are not offering Direct Payments, are not promoting the benefits but stressing any possible negatives, and are not informing carers of the independent support available to them, wherever they live in Hampshire. The service is not yet available in Southampton or Portsmouth. Carers who have found the benefits of Direct Payments have often accessed the Carers Together Direct Payment Support; several carers who had found difficulty stated that they did not know the service was available. Action to expand the service and ensure that all carers are aware of their right to independent advice is needed.

Hospital Discharge

There is fear that the system of charging Social Services for bed blocking by clients deemed to be ready for discharge will mean loss of choice for patients and carers, especially as the assessments are often done without reference to, or input by, the patient or carer. One of the essential activities as a result of this consultation seems to be the need to identify where the communication is breaking down, why patients and carers are not being given choice, ensuring that the views of patients and/or carers are taken before making decisions and working with a range of other groups and agencies to develop a realistic inclusive process of assessment for discharge that does not exclude the patient and/or carer or make assumptions about the result.

Information

The need for independent comprehensive information and support in accessing and preparing for the assessment process was identified. Carers Together has produced a Carers Pack, with lots of independent information that is available to carers on request. The information is constantly being

updated and includes information about Carers Together staff, an A to Z of useful contacts, useful benefits help-lines; leaflets on how to get support, what it is like to be a carer, a copy of the current issue 'Do You Care', a Carers Guide to health, housing and social services, community support, finance and money matters and legal issues about caring. Information about services available in different localities is also being developed.

Carers Together is developing an Information Resource that will be available to carers from all over the county who wish to access information about any aspect of caring including legislation, helpful books, leaflets from a wide range of groups that support carers (directly or indirectly). It is anticipated that the information available will be expanded and made available widely both during and out of normal office hours. Future action includes ensuring the information is maintained and up to date, accurate and widely available, taking innovative action to ensure that carers are informed about its availability and supporting them in accessing and using the facilities on offer.

There is Guide to Carers Assessment which takes carers through the process from finding out how to request an assessment, preparing for one and ensuring the result reflects what the carer needs. It is available to carers on request.

The development of Carers Awareness Courses, undertaken with statutory and other voluntary organisations across the county in a friendly and informal setting, would assist this process and help carers, particularly new carers, to become more expert in their role.

Respite

Respite covers so many different aspects and the need is different for every individual. Everyone appreciates that respite is essential for carers and that the level of resources very often determines the level, length and availability of respite. One of the problems seems to be that respite is very often based on buildings or services available such as residential homes or day centres, home care or sitting services. Although these are essential and welcome, the fact that the commissioning agency is very often the provider agency means that they have a vested interest in seeing them used fully and it can limit the flexibility of respite on offer.

Respite can mean so many things to different people that it cannot be measured in hours or days available. More access to Direct Payments will mean that carers will be looking for more flexible and innovative respite arrangements and many now have positive suggestions for their own respite and the respite of the person they care for, which would save money, and give them more choice if they were able to implement them. Further consultation and research into available and potential respite may be useful and positive and enable carers to access more flexible and innovative schemes.

Support

There is no single way of supporting carers. Every carer is different and has different needs. Most statutory organisations are limited in their provision of services by the resources available to them and this can sometimes affect their independence when suggesting services and support. The services and support therefore can be resource and service provision led which limits the range of solutions available. One of the needs of carers is to find out everything that is available to them before having an assessment, seeking innovative and different solutions to their concerns, accessing comprehensive information, having independent advocacy and being able to off load their concerns to an independent non judgemental person. This level of independent support would enable carers to continue caring or to make informed decisions on whether not to carry on caring without being tied to traditional support services. The development of a broad based Carer Support Service which is independent, holds comprehensive information, is prepared to listen to concerns and empathise with stresses, and is available during the day, evening and at weekends would be a positive step towards improving support for carers.

Appendix 1 Carers Support Services – Notes from Workshops

NB By Carers Support Services we meant any service that helps a carer continue to care not only those with that label

Negatives

- Carers need choice - hospital discharge needs remove this choice.
- Carers don't get listened to.
- Carers - Access for new carers – to information about carers support services.
- Carers - Carers need to be informed automatically by both health & social care. Confidentiality quoted - need to share patient/client information with carers. Triangle of consent possible but few signed up to it.
- Carers - How do you find out what is available?
- Carers - Lack of carers assessment – not offered to carers or not finished and signed
- Carers – made to feel guilty and responsible by NHS staff
- Carers - Remote carers are invisible except when there is a crisis (if don't live with relative)
- Carers need choices
- Carers need to feel valued
- Communication – if you do not know who or what to ask - you will not get the answers.
- Day Surgery has no connection with the outside world!
- Difficulty in contacting Social Services and getting access to a social worker
- Direct payments - lack of people to employ in north of county.
- Disparity between areas – in what is offered and available
- Hospital - So many notes (hospital) but nobody reads them.
- Hospital Discharge – After Day surgery. No assessment is done before patient admitted for the day surgery, in case they are unable to manage on returning home. It is assumed a carer will pick up the pieces!
- Hospital Discharge - Carer is last to be told anything prior to discharge.
- Hospital Discharge - Discharge from hospitals on Friday a particular problem - no care arranged. Care Package often to start on Monday. Weekend care is patchy and irregular.
- Hospital Discharge - Information provided too late by hospitals (should be planned discharge in cooperation /consultation with carer – transport, equipment should be provided)
- Hospital Discharge - Pressure from hospitals to discharge over Christmas – often no assessment or discharge packages
- Hospital Discharge - Rigid systems - non-availability of Community Psychiatric Nurse if no Care Programme Approach from hospital
- Hospital Discharge over weekend/Holidays - a problem, it is assumed the carer will manage
- Information is there but access to it is a real problem.
- It is a daughter's duty to care! (Assumed by professionals)
- Lack of choice of day care.
- Lack of communication – Health and Social Service Department
- Lack of communication between Social Workers and Carers. Information not passed onto carer.
- Lack of communication between Voluntary Organisations and Services. Need to talk to one another to avoid duplication.
- Lack of Occupational Therapists and lack of Physiotherapy unless trauma case.
- Lack of resources for respite
- Lack of respite, more carers getting less time, sometimes reduced to two hours. E.g. Need 24 hour care, offered three hours to 'enjoy' yourself! Not enough time to go out on public transport
- No night sitting available - Overnight care very limited "too expensive".
- Nobody in the room happy with care packages. Not getting what they would like.
- Paid Carers - and other staff - should carry I.D – many do not and cannot produce when asked.
- Paid Carers – Carer Continuity – ideally should have the same carer especially sight impaired.

Appendix 1 Carers Support Services – Notes from Workshops (continued)

Negatives (continued)

- Paid Carers - late or not enough time allotted to that job. Carers having to travel in their own time - travel time not allowed for.
- Paid Carers - not allowed to do what is needed (moving and medication). Husband had to be present when medication given!
- Paid Carers - Not enough paid carers to do the job.
- Parent carers struggling to get all they need. Especially respite care.
- Pool - Knowledge and resources.
- Services are reactive rather than proactive.
- Unidentified carers that are self funding slip through the support network.

Positives

- 'Do You Care' (Carers Together Newsletter) – there's always something in there!!
- Adult placement – when available.
- Alzheimer's Café (Farnborough)
- Carers Assessment - Guide from Carers Together
- Carers Assessments
- Carers Centre and Home Information Service (Eastleigh)
- Carers Forums – local and independent
- Carers Forum Romsey - identifies gaps in services and accesses funding to meet these gaps e.g. Romsey Area Information Network, Young Carer Befriending
- Crisis intervention - Melbury Lodge
- Direct Payments – allow choice and continuity of carer.
- Direct Payments Support from Carers Together for carer to set up scheme
- District Nurses and Community Mental Health Team (CMHT)
- Formal complaints produce results quickly.
- Good input from services but lack of information - about stopping them.
- Home/school co-ordinators at special schools
- Local carer contacts – carers' mutual support networks.
- Local Carers Groups
- Macmillan nurses
- New GP contracts encourage more contact and register of carers in surgery
- Paid Carers become friends – continuity of carer helps.
- Patient Advice and Liaison Service, accessible and information available in hospitals.
- Preventative care to help keep person out of hospital, e.g. Elderly Person's Integrated Care Scheme and Rapid Response Teams.
- Some paid carers are very good – become friends.

Suggestions

- 'Do You Care' – Needs to be made available wider
- Special supplement sometimes needed for Carers Together Newsletter e.g. update on day courses on special needs, or item giving details of Patient Advice and Liaison Service contacts. (There are financial implications)
- A listening ear – telephone service
- Affordable/cheaper sitting services
- Bring back Hospital Almoner
- Care Information before Discharge - planned together
- County wide volunteer bureau – to train volunteers – to support carers and cared for.
- Funding at grass roots in localities of natural population

- Information in lots of formats – information on the internet is not available to all

Appendix 1 Carers Support Services – Notes from Workshops (continued)

- Listening to what people want.
- Local carer contacts – carers mutual support networks.
- Local Carers Forums – should be in every locality and linked through Carers Together, a consortium of carers across Hampshire
- Means testing - Delay in means testing – may mean a delayed (large) bill. It needs appropriate means testing – at an early stage and reviewing at regular intervals.
- More choice of day care.
- More day care
- More facilities for early (under 65) dementia
- More Occupational Therapy aids.
- More respite care – different, flexible
- Powers of Attorney make things simpler for Carers.
- Pressure groups to work together.
- Rapid response teams – should be everywhere.
- Should there be a carer database?
- Sitting services, which replace the carer.
- Too many chiefs and not enough Indians. Get management to see problems at grass roots – may make them change some of their policies.
- Unmet needs should be recorded – possible as desirable action – need to be reported to government and/or used by commissioning authorities to commission new services

Workshop 2 – How do Carers Want to be consulted – Notes from Workshops

Negatives

- Carers are often talked at rather than consulted, when attending advertised consultation events
- Carers do not feel listened to
- Consultation on services often bypasses the individual carer
- Lack of information from GPs/hospitals/social workers makes informed decisions difficult
- Lack of knowledge about consultations, which are taking place
- Lack of range of formats limits access to consultation
- Limited Consultation with carers themselves when packages of care being arranged
- No action noted as result of consultation events - not told the results.
- No feedback from consultation events
- Training needed for people on the ground i.e. professionals to ensure consultation is meaningful.

Positives

- Feedback from Local Implementation Group.
- Feedback on action and results of consultation makes it worthwhile
- Local consultation for local issues e.g. Information and Consultation Day in Test Valley in 2003
- Provide a pleasant experience (Melbury Lodge).
- Providers and professionals attending groups.
- This consultation event – opportunity to speak openly

Suggestions for Consultation with Carers

- Carers need to feel they are listened to
- Carers need to feel valued – pay expenses and extras for them to go to meetings and consultations (Publish in 'Do You Care' - Hampshire County Council Social Services Department's expenses procedure).
- Feedback from this consultation will be sent to NHS, DoH and Service Providers
- Need to be consulted not talked at
- Carers independent telephone service would provide independent information and consultation.
- Consult through Carers Forums and Carers Groups
- Consult through the letterbox.
- Consult by telephone, may be a good idea, could work well, preferably independent organisation
- Consultation - need different methods for different people.
- Consultation - need information first – before consultation to allow time to consider.
- Consultation - rolling programme of consultation would be useful with feedback and action taken from previous ones
- Consultation days are helpful – but timing is critical
- Consultation needs resources – time and money.
- Questionnaires - not always so good – if not returned make it of less value – time factors interfere – carers too busy.
- Services need to listen to carers when carers want to speak.
- Should carers who are regularly involved in meetings or consultations be paid a fee for their work? What about conflict of interest
- Timing of all consultation is critical.
- Use Churches, Community Centres, Village Halls, Town Halls etc.
- Use Flyers, posters, feedback evaluation forms completed when carers using services.
- Use GP Surgeries - new G.P. contracts encourage identification of carers.
- Use Libraries, Mobile Libraries, Post Offices, Media - TV/Radio News/Press
- Value of e-networks – possible but questioned.

Report circulated to:

Carers

Carers Groups

Voluntary organisations in Hampshire, Portsmouth and Southampton on the database

People in Hampshire who have registered an interest in Carers issues

Hampshire Social Services

Aldershot and Farnborough Social Services

Basingstoke and Alton Social Services

Eastleigh/Romsey Social Services

Gosport and Fareham Social Services

Havant and Petersfield Social Services

New Forest Social Services

Portsmouth City Social Services

Southampton City Social Services

Winchester and Andover Social Services

HIW HA

Blackwater Valley and Hart PCT

Blackwater Valley and Hart Patient and Public Involvement Forum

East Hampshire PCT

East Hampshire Patient and Public Involvement Forum

Eastleigh/TVS PCT

Eastleigh/TVS Patient and Public Involvement Forum

Fareham and Gosport PCT

Fareham and Gosport Patient and Public Involvement Forum

Mid Hampshire PCT

Mid Hampshire Patient and Public Involvement Forum

New Forest PCT

New Forest Patient and Public Involvement Forum

North Hampshire PCT

North Hampshire Patient and Public Involvement Forum

Portsmouth City Teaching PCT

Portsmouth City Patient and Public Involvement Forum

Southampton City PCT

Southampton City Patient and Public Involvement Forum

Winchester and Andover PCT

Winchester and Andover PPI Forum

Hampshire Ambulance Service NHS Trust

North Hampshire Hospitals NHS Trust

North Hampshire Hospitals NHS Trust PPI Forum

Portsmouth Hospitals NHS Trust

Portsmouth Hospitals NHS Trust PPI Forum

SUHT

SUHT PPI Forum

West Hampshire Trust

West Hampshire Trust PPI Forum

Winchester and Eastleigh Healthcare NHS Trust

Winchester and Eastleigh Healthcare NHS Trust PPI Forum

Carers Together

Carers Together is the consortium of Carers in Hampshire. It has been operational for ten years and has its base in Romsey. It provides an information resource and a listening ear for carers; provides a Carers Pack and Assessment Pack to help carers; issues a regular newsletter widely across Hampshire; works with disabled people/groups on issues affecting users and carers; holds consultation meetings and seminars countywide for carers. It employs development and support workers to work with carers giving support, information and signposting, identify services available for carers and develop and promote services to meet gaps. It also employs independent Direct Payments Support Workers to help and support individual carers with their Direct Payments scheme.

It aims:

- *To involve Carers from all areas of Hampshire regardless of whom they care for*
- *To develop the profile of carers and ensure their voice is heard*
- *To recognise the expertise of carers and ensure this is used effectively*
- *To give support to all carers and carers groups in the county as required and provide a countywide support network*
- *To empower carers and work for carers inclusion in all areas of decision making*
- *To enable carers to discuss, co-ordinate and represent their needs county wide*
- *To gather and collate information and share this with carers and carers groups*
- *To ensure that carers are involved in all stages of planning, development, implementation and review of services*
- *To advocate for carers and ensure they can benefit from advocacy services*
- *To improve the quality of life for carers and the people they care for by providing an independent non judgemental listening ear to enable carers to offload*

Involvement of Carers

The management committee of Carers Together consists of carers or former carers whose experience of caring is invaluable. There is continual consultation with carers and carers groups on issues affecting carers and those they care for. This includes regular consultation seminars that also provide opportunities for carers from each locality to meet and to share their views, news, needs and seek mutually beneficial solutions. Carers have the opportunity to input into the newsletter, are encouraged to join committees for planning, development, monitoring and review of services for themselves and those they care for and to feed back into the countywide network. This includes becoming involved with consultation and service provision as well as with activities influencing social work practice.

The organisation has a commitment to the belief that carers should be supported according to their needs, sometimes by other carers, sometimes by paid workers and sometimes by volunteers. Carers have the right to represent themselves and, where appropriate other carers, and should be assisted and encouraged to do this whenever possible. It is developing a varied programme of services, training and activities for carers and workers to access that are supportive, practical and sometime fun – e.g. consultation, information, relaxation, signposting, training tips, creative activities etc. This includes CLICK, which is an email support group for carers who live across the whole of Hampshire. Carers can link with each other at any time of the day and night, and it enables them to be consulted and considered on any topic or issue. Carers are active members and are able to share information across a wide range of disabilities and to discuss good practice in different localities.

DECEMBER 2003

REPORT CONCERNING

THE CONSULTATION

WITH CARERS

IN

HAMPSHIRE

24 October 2003



Further copies are available from
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