

# GetInvolved



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## Adult and Community Services takes User Involvement seriously

The adult and community services Directorate within Herefordshire Council has made a substantial commitment to the user involvement agenda within health and social care by recruiting for a user involvement assistant.

Richard Gallagher has been employed to undertake this role on a full time basis and it's the first time this kind of position has been created specifically within the Council.

Richard takes up his new position in June and is looking forward to the challenge of developing this role so that service users can assist in informing on service provision and help shape the future of adult social care in Herefordshire.

The role will involve a large amount of survey work that is both statutory and locally generated but will also give Richard the opportunity to develop focus groups and various fora amongst the users and families of users within the County. There is also a need to research various themes such as

satisfaction rates, Home Care provision and various funding issues and Richard has some excellent ideas on how to explore these issues.

Richard will be joining a team known as the Public Contact team that is dedicated to collating, researching and reporting on all types of user feedback from complaints and comments to compliments and user dissatisfaction. The remit of the team is to;

- Provide a set of relevant and up to date leaflets about the services offered by adult social care and strategic housing
- Review the information currently displayed on the Social Care pages of the Herefordshire Council website and to make proposals for development

- Review existing complaints procedure ensuring conformity to planned changes from Commission for Social Care Inspection and Department for Education and Skills
- Develop a programme of activities to enable feedback and involvement from service users and other stakeholders
- Enhance internal communications within and across Adult and Children's Social Care and Strategic Housing

It is clear the team face a huge challenge in the coming year and they all look forward to working positively with service users. It is hoped that their work will help in informing service provision and create a culture whereby the citizens of Herefordshire feel they are empowered to help shape their futures.

Please contact Tony Homden on 01432 260176 for further information or e-mail him on [thomden@herefordshire.gov.uk](mailto:thomden@herefordshire.gov.uk)

Welcome to the third issue of the newsletter.

We have received positive feedback about this new style newsletter and hope that you are enjoying reading it too. Please pass your copy on to friends and colleagues to spread the news about how involvement is helping to improve health and social care services for all. Obviously, we need you to send us news about what involvement work you are doing – our contact details are on the back cover. We look forward to hearing from you.

Helen Lee and Tony Homden

Herefordshire   
Primary Care Trust



### Get Involved

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# Some examples of ways that people with dementia are involved in the Alzheimer's Society



Since the year 2000, the Alzheimer's Society has been working through a national programme called "Living with Dementia" to involve people who have dementia in its work and decisions. By talking and listening to people with dementia, finding out their views, concerns and experiences, we have much more understanding about the needs of people with dementia. People with dementia have also influenced our development of products, services and policies, and have been raising awareness at a national and a local level.

These are some of the activities that people with dementia have been engaged in:

## Keeping a diary

Peoples narratives contain a wealth of information. Although these are individual accounts, there are

often common themes that emerge. People have kept diaries with words and photographs and using tape recorders.

## Developing information for other people with dementia

A very enthusiastic and determined group of people helped me to write an information booklet for people with dementia. Using quotes and tips they demonstrated the ways that they live with dementia, rather than staff at the Alzheimer's Society advising the best way forward. The determination of the group was very useful as we negotiated design and layout with the designers. The will of people with dementia won out against artistic temperament! Over 30,000 copies of the information booklet "I'm Told I Have Dementia" have been distributed since its update in 2001. The booklet receives consistently good feedback from people with dementia, and has complementary information sheets to go with it.

## Filling in questionnaires about services and future planning

A short questionnaire was developed to assess the satisfaction of people with dementia with a counselling service provided by the Salisbury branch of the Alzheimer's Society. The questionnaire contained instructions about how to complete it and draws attention to the sections that people have to answer by colouring them red. It also talks about the project in familiar terms to the person with dementia e.g. by naming Elizabeth rather than calling her a counsellor. In terms of the distribution of questionnaires we have learned that we get more response if the subject matter is of interest/relevance e.g. the subject matter 'getting a diagnosis' elicited a lot of response for people with dementia. It is important not to feel like you have to ask absolutely everything in one go. Too many questions can be overwhelming - choose the ones that are the most important. People may need help to complete the questionnaire. This may impact on 'scientific interpretation' but gives you access to views that you might not otherwise get

## Attending focus group meetings

Bringing together a small number of people with dementia to discuss an issue can be a useful way to elicit views. People have attended groups to discuss how supermarkets can be organised to be more 'dementia friendly', what it feels like to receive a diagnosis, memory tips and techniques, among other things.

## Giving presentations

A small number of people have been willing to speak at public events about their experiences with dementia. These include people who have past experience of public speaking (perhaps in their work) or who would like to accept a new challenge, with the right level of support. The common motivator is the desire to raise awareness. Audiences are often made up of people who have never heard someone with dementia speak about their experiences in this way. It is a significant way of challenging misconceptions and educating people.

## Commenting on government legislation

Comments from people with dementia are included in Alzheimer's Society reports to government bodies such as the Department of Health. This was particularly influential in a submission to the National Institute for Clinical Excellence (2000) regarding prescribing the drugs for Alzheimer's disease.

## Learning how to use computers

We have been running computer-training sessions with the media arm of Community Services Volunteers (CSV). Volunteers have been providing one-to-one support to teach people to learn a new skill, including using email and the internet. The West Kent branch of the Alzheimer's Society runs a computer project enabling people with dementia to use computers to access interests, reminisce and have fun. People with dementia have also set up a branch website, with pages of special interest to other people with dementia. See [www.alzheimers.org.uk/westkent](http://www.alzheimers.org.uk/westkent)

## Planning activities in a local branch

At one branch day centre, people begin their day by coming together in a 'community meeting'. Clients take turns being responsible for chairing the meeting or reading the minutes with help, if needed, from another client or a member of staff. This provides orientation to day and place, whilst a roll call allows each client, present or absent, to be acknowledged. Business discussed can cover decisions concerning everything from acceptable conduct to what equipment to buy to where to go on the next outing.

## Rachael Litherland

Alzheimer's Society, Living with Dementia programme manager

# Pain Management Programme

**Patients who have learned about self-management techniques through attending a Pain Management Programme, are helping others to learn how to cope with chronic pain.**

The 'Pain Graduates' have helped others by coming back and talking to new patients about the skills they have learnt and ways that the programme has helped them cope with their pain.

Patients who have been on Pain Management Programmes have been instrumental in making changes to the service. They have been involved in developing a new Introductory session for patients and their relatives which lets people know what pain management is about.

The increased involvement of patients in collaboration with the combined Gloucestershire and Herefordshire Pain Management Service is highly valued by the multi-disciplinary professional team of physiotherapists, nurses, psychologists and occupational therapists.

Gaynor Raine, Pain Management Nurse with the service, explained:

"By involving patients in a collaborative way, we feel that this has led to a cultural shift across the service. Patients are seen as partners with their

own unique contribution to tailoring services to meet the needs of users, leading to service improvements."

The service offers about five pain management programmes each year to help those with chronic pain to understand it better and to develop their own self-management strategies. Gaynor says that participants find it invaluable to hear the accounts of the 'pain graduates' from previous courses.

"They still have to cope with pain on a daily basis but can explain how they have developed skills that have really made a difference."

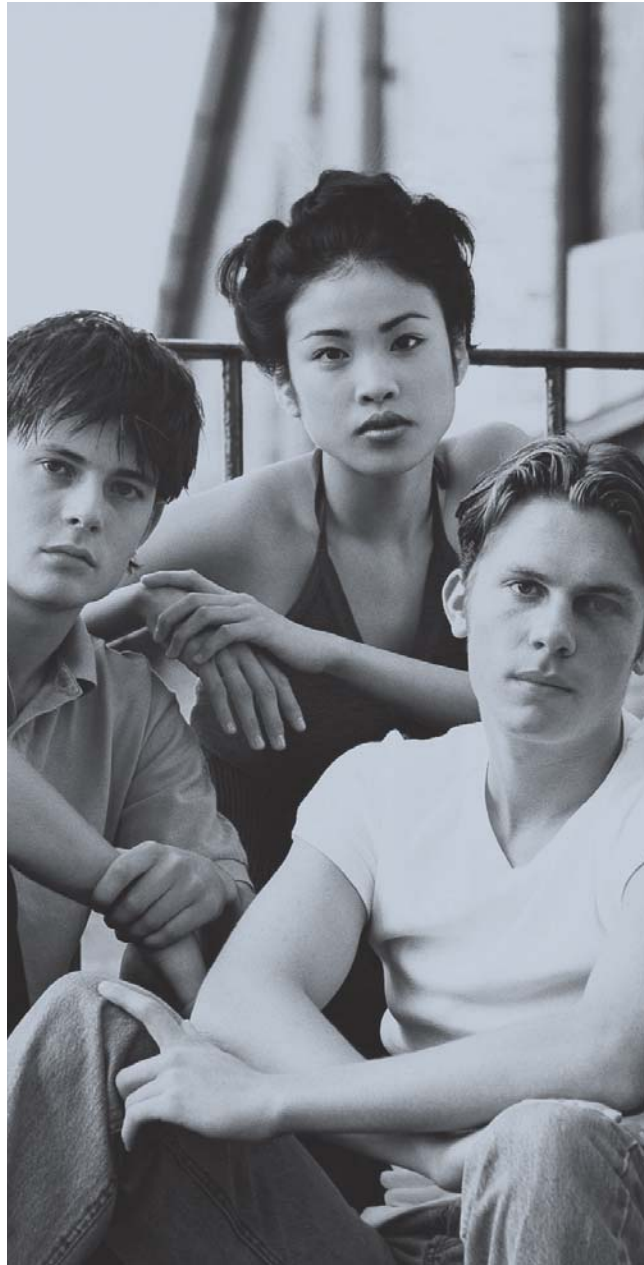
**Another development planned by the service is to involve patients' families and friends more, as Gaynor points out that they can feel isolated and confused and would also benefit from involvement.**

**Sue Hurrell (pictured) had not managed to paint for many years because of her pain, but got back to it after attending the programme last year and produced this wonderful painting which she kindly donated to the service**



# “Voices”

## Enabling young people in Herefordshire Council’s care to make a positive contribution



**Voices activity, in terms of improved outcomes for young people, links with and supports all five of the Every Child Matters ambitions.**

### Voices principle aims are to:

- Consult with and listen to young people in the care of Herefordshire Council
- Ensure their views are taken seriously, are heard by decision makers and make a difference to services
- Extend opportunities and enable them to develop skills and confidence

Four years in development, Voices already has an impressive track record of activity and achievement. The young people who have contributed to Voices so far tell us that it works for them because they:

- Meet with others in a similar situation
- Have fun and learn new skills
- Share views on what is working well and what needs to change
- Have the opportunity to help others in care
- See how their input is making a difference to the way things work

Two part time participation workers work in partnerships with others, principally the Children’s Rights and Advocacy Officer and a children’s consultation worker originally employed by the Patient Advice and Liaison Service (PALS) currently working on a sessional basis. Foster carers, social workers, support workers, managers and elected members have also made valuable contributions. The benefits of these links have been immediate and obvious.

The Children’s and Young People’s Services Directorate provides core funding of £35,000 per annum to support the work of Voices. This covers the two part time staff, publication of the quarterly Voices magazine which is written, designed and produced by and for the young people themselves, taxi fares for the young people to attend groups, and associated expenses including refreshments and direct payments for them for specific pieces of work. A laptop has been purchased for the young people’s use from this budget, and any surplus is used to support the annual celebration event for looked after children, organised in partnership with the Education Liaison and Support Service.

Successful funding bids have recently been made to a local charity and to Herefordshire Council for Voluntary Services. Grant funding from these sources will be used to support additional cultural and developmental activities for the young people.

Voices aims in different ways to reach all children and young people between 5 and 19 who are in the care of the Council, placed both within the county and further afield.

Particular care has been taken to include elected members, partner agencies, carers, teachers, managers and social workers in the development of the project to promote a shared and constructive approach to the issues the work has raised. Members of Voices are now well placed to play a significant part in the local change agenda for children.

Before the development of Voices children and young people tell us they were unaware there were so many others in a similar situation in Herefordshire. By offering them a chance to meet and/or read the newsletter written by and for their peers we have provided opportunities to form social networks that are essential for healthy development of identity.

The national Every Child Matters agenda has been welcomed as an additional driver and framework for activity at local level.

Creativity and enjoyment form a part of every session with the young people, and a range of approaches - from rap music to art and creative play - have been used to engage different age groups and different individual needs

A typical meeting will be divided into sessions of task-focused work, and free time for the young people to socialise and enjoy each others company.

Careful pre-planning for all meetings has proved essential, as has recording and clear action planning as a result of each session.

Support from care leavers has been particularly valuable. Examples include their involvement in videoing young people’s first ventures into making music at the Courtyard and setting up a ‘Big Sister’ room at this event for individuals to come and talk in private if they wanted to.

Care leavers have also been involved in developing a presentation for younger children on what it might feel like to come into care for the first time. This piece of work, which used animal cartoons to carry the story line, proved a great success with 8 – 13 year olds, who immediately identified with the characters and

were able to think of ways they might be helped to feel better about what was happening to them. Meeting with others in a similar situation has been visibly reassuring and enabling for many of these young people. As well as having a good time together they have in different ways revealed exceptional altruism and ability to support each other.

Many have worked exceptionally hard to meet deadlines and produce high quality work. Significant achievements this year have included:

- Hosting the launch of the Pack Attack (a box for personal effects for children going into care for the first time and speaking confidently to groups of social workers and managers about their development and proposed use
- Creating a set of colourful pieces of artwork to liven up the room for Great Expectations, the November celebration event for young people and their carers
- Taking responsibility for welcoming newcomers to Great Expectations, helping them write messages on stars for the newly launched Listening Tree, and interviewing significant adults during the proceedings as roving reporters.
- Meeting the Lead Member for Children’s Services on several occasions and expressing their views clearly and confidently
- Interviewing, as a separate panel, candidates for the aftercare team manager’s post and contributing constructively to decision making on the appointment
- Participating in a County-wide consultation to launch the ‘Shadow Partnership Board’, a young peoples’ forum which will directly inform the Children and Young People’s Plan for Herefordshire, and achieving three places on the 20 strong Board.
- Sustaining the Voices magazine through changes to the editorial board, and launching the first separate version for younger children.
- Supporting and enabling each other to join in and make a positive contribution to activity and working sessions.

Features on the work of Voices appear regularly in the Council’s Core News which reaches all Herefordshire employees, and Herefordshire Matters, delivered to all households in the county. Information reaches other young people in care via the Voices magazine, now in junior as well as senior formats.

**For more information please contact Sophie Hughes on 01432 260072 or e-mail her on [shughes@herefordshire.gov.uk](mailto:shughes@herefordshire.gov.uk)**

# Training dates for your diary

**In the last issue we told you about training opportunities from the Involving People Team available to service users and carers. We are running the training modules throughout the year and are just coming to the end of the summer sessions, which have been well supported. Our dates for the autumn are as follows:**

- Who's who and what they do in the Primary Care Trust –  
Thursday 28 September  
10a.m – 12 noon
- How to make difficult decisions –  
Wednesday 25 October  
10a.m -12 noon
- How meetings work –  
Tuesday 10 October  
2pm - 4p.m.
- Sitting on an interview panel –  
Wednesday 8 November  
2pm - 4.30p.m.
- Looking at disability in a different way –  
Tuesday 21 November  
10a.m -12 noon.

The venues for the training have still to be decided depending on numbers of interested people. Please get in touch if you would like to find out more about any of the training sessions or to book a place on 01432 262016 or email: sue.pritchard@herefordpct.nhs.uk

Don't forget we can pay your out-of- pocket expenses, such as travel costs, so that everyone is able to attend. Let us know if you have ideas for other training you would like us to develop. We hope to see you in the autumn!



# User involvement in Cancer Services

- **Have you ever thought that you would like to be consulted about the services you use?**
- **Do you get frustrated when things seem to be out of your control?**
- **Is there any change that you think would have made your experience better?**
- **Or was your experience very positive and you feel that you would like to 'give something back'?**
- **These are the sorts of questions that people who 'get involved' are interested in.**

## Background

In 1995 a report by the Expert Advisory Group on Cancer (The Calman Hine Report) stressed that cancer services should be patient-centred and that decisions at all levels should take account of patient views. The National Cancer Plan followed the report in 2000 and talked about the importance of empowering patients to improve services. To ensure that this was taken forward, the Cancer Partnership Project (CPP) was set up in 2001, jointly by Macmillan Cancer Relief and the Department of Health.

## Cancer Patient Partnership (CPP).

The CPP set out to bring well-trained service users and professionals together within cancer networks to influence service planning and delivery. Since the project began, 30 of the 34 cancer networks in England have established Partnership Groups at network level. The majority of Networks now have User Involvement Facilitators to support these groups.

## Being part of a Network User Group

So what does it mean to be part of a Network User Group? Obviously meetings! The frequency of these can vary from monthly to quarterly but a lot goes on in between too. Groups may be based in localities or there may be one central group in the network. The groups comprise patients, ex-patients, carers and ex-carers working with a facilitator and health professionals who may be specialist nurses, service improvement staff, consultants and

management staff. The groups have links to the network boards and can have a real influence on decision-making.

## Training is available

To help members, training is available through Cancer VOICES which is supported by Macmillan Cancer Relief. This is a fun two days where users and professionals learn to understand each other, gain confidence in working together and practise putting together a case for change.

## What actually happens

Locally, groups work to make improvements in their own cancer networks, working on such things as opening support centres like Maggie's in Edinburgh, setting up new patient information centres, parking issues, transport problems for people trying to get to cancer centres from remote areas you name it! The amount, quality and timing of information given to patients are a hot topic at the moment. As consumers of the information we need to know what your requirements are. User groups have worked to get pagers put into waiting areas so that patients can go out during their waiting time, and made other improvements to the waiting area environment. They have helped to carry out surveys of patients' views, set up information centres and so on.

Members often get involved in other things as well such as Ambulance Trusts and Foundation Trusts – the opportunities are endless! The groups are also a means of consultation on initiatives by the trusts in which they work. They may be asked for their views on anything from nurses' uniforms to the siting of particular services. Many groups are involved in ensuring that services for cancer patients are moved out to more local hospitals to help alleviate travel problems and overcrowding in the waiting areas.

## Other opportunities to get involved

For some, local involvement is only the start, there are opportunities to become part of national programmes and initiatives, especially with Macmillan Cancer Relief; for example, the Gold Standards Framework is a programme for GP surgeries that ensures good continuity of care during the later stages of life. Recently, a group of ex-carers has been putting together a pack specifically for carers to support them in their role; Hello and How Are You\* is now available from Macmillan. If public speaking is your forte then there are national conferences that would definitely be able to use your talents!

Get involved yourself – you can make a difference! Partnership and locality groups are always seeking new members. If you have an interest in wider issues and feel that you have something to give for the benefit of all cancer patients and carers please join us. If you answered yes to any of the questions at the beginning and feel that involvement is for you then please get in touch with your local Partnership Group via the Cancer Network. They will welcome you with open arms!

A recent evaluation of the Cancer Patient Partnership (CPP) found that members of groups felt that they were making a difference to local NHS cancer services. One user member said: "Once you are told you have cancer you don't think you have any ability to give anything back, and even those people who are terminal have this great opportunity to actually feel empowered. From something which is the worst thing that can happen to you can actually re-change your life, can make you.... significant, it can make you fulfilled."

**So please – GET INVOLVED – you can and will make a difference to others and yourself! For further information please contact Dr Jane Grant at the Three Counties Cancer Care Network based in Cheltenham.**