

# the value of getting involved



Issue Number 6 - Summer 2007

## Herefordshire Service User Network

Herefordshire Service User Network (SUN) was originally set up by Herefordshire Centre of Independent Living as a peer support group to enable direct payment users to meet and offer mutual support and advice to each other. The group has now become independent and secured its own funding and is open to every disabled person.

SUN is run by and for disabled people; it is an open, friendly and welcoming group where members can:

- openly discuss their views and share their experiences of independent living in Herefordshire
- use their wealth of experience and knowledge to offer practical advice and solutions to problems
- offer confidential peer support
- exchange information and ideas with other groups

- take part in wider involvement work and consultations with public sector organisations, such as Herefordshire Council or Primary Care Trust to ensure better service planning and delivery.

SUN meets on a Tuesday every 6 weeks at 11am-1pm (lunch 1-2pm), usually at St. Martins Church Hall, Hereford.

SUN also has 3 social meetings per year and the last one was a picnic in July in the grounds of the South Wye Learning Centre. Maria Cornell reports "this year's picnic was a great success and a great opportunity for people to socialise and network with each other."

**If you would like more information on the above please contact: the group facilitator, Maria Cornell on 01544 387956 (email: [dweezer@tiscali.co.uk](mailto:dweezer@tiscali.co.uk))**



### This issue includes:

- Helping hand from a distance 02
- PALS – how problems can lead to involvement 03
- Eat your way to health 04
- Questioning attitudes 06
- How people are influencing intermediate care services in Herefordshire 07

**Get Involved**

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# Helping hand from a distance

Telecare is an exciting and innovative service which provides support to people in their own homes

Allowing people to remain in their own homes and independent has been a key priority for Herefordshire Council. One of the initiatives Telecare or Preventive Technology as it is also known and now the service is looking for User Involvement to help shape the way in which this service is presented and delivered.

Telecare is an exciting and innovative service which provides support to people in their own homes, with the help of technology and community response services. Unintrusive and flexible, it is a remote monitoring service which can help transform the lives of those who wish to remain living in their own homes for as long as possible. It can bring reassurance to users who can now have immediate help available, 24 hours a day, 365 days a year, at the touch of a button!. Sensors include smoke detectors, fall detectors, flood detectors, a bogus caller button, wandering client alarm, carbon monoxide detector, temperature extremes sensor and a medicine/pill reminder.

Within the telecare team it has been decided to investigate the use of a SMART House, where a property will have live sensors and detectors installed that are connected to the monitoring centre. They will be used for live demonstrations of the system and visits for those interested in learning more about Telecare. They would also be used by social care for assessment and reablement purposes.

Another development is Telemedicine, which works by monitoring vital signs such as blood pressure, blood sugars, pulse etc. The data is then transmitted to the clinician's computer where it is closely monitored ensuring a constant picture of a person's health and well being and alerting clinicians to problems.

As this new way in helping people remain independent is though it's trail period, User involvement is now taking an active role in the future of Telecare and it's evolution. A satisfaction survey is to be sent to all service users to ask how they feel about the contact, set up and service they received.

With the survey is a letter asking for members to join a forum made up of service users and key people involved with preventative technology. This forum will directly feed into the way the service is delivered and look at ideas such as the SMART house to make sure that this delivers what service users expect and to give a users point of view of this helping hand from a distance.

# PALS

## how problems can lead to involvement

An evaluation of the community healthcare PALS service in Herefordshire earlier this year showed that patients valued its role in helping them sort out their problems; understand their options; feel reassured and offering support, and for a few it was an alternative to lodging a formal complaint.

It was equally appreciated by healthcare staff who recognised its usefulness in providing an impartial service and on occasions mediating to resolve difficult situations. Many healthcare professionals confirmed that they had introduced changes as a result of PALS cases, where this was beneficial.

We actively encourage patients to raise their concerns with PALS because not only does it help sort out their own case, but it may well identify the need for change that will help others using services in future.

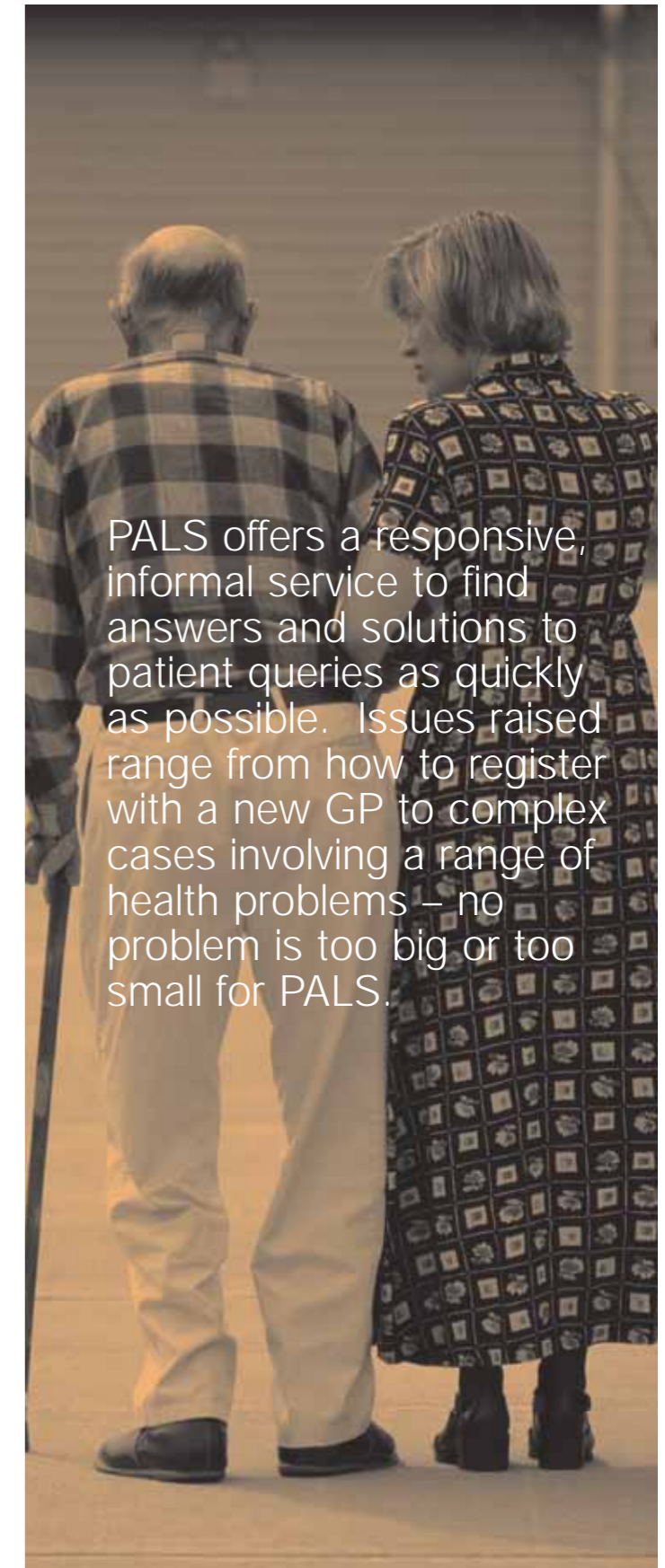
Recent PALS cases have included a family affected by delays in making progress on adaptations to the home after a stroke; a person with a long-term health condition who found the wording upsetting in a GP letter drawing attention to help for depression; and a parent who was concerned about the length of the waiting list for her child to be offered an orthodontic appointment.

Although some people have come to PALS with a negative experience if an aspect of health care has not worked for them, a number of them have turned it into something positive by subsequently joining our 'Involving People Network' and

PALS offers a responsive, informal service to find answers and solutions to patient queries as quickly as possible. Issues raised range from how to register with a new GP to complex cases involving a range of health problems – no problem is too big or too small for PALS.

recognising that they can have a voice and help to make a difference.

**To contact PALS, telephone: 01432 262016 or write to PALS at Victoria House, Eign Street, Hereford HR4 0AN**



# Eat your way to health

Cancer patients from Herefordshire recently took part in filming for a DVD being made at the instigation of Linda Taylor, a cancer patient from our Cancer Network.



Linda who suffers from a rare cancer called an epithelioid haemangioendothelioma and who had to travel to the US for her treatment identified a gap in information provision for cancer patients. She had lost 3 stones in weight while having diagnostic tests and found it very difficult to keep food "down." She discovered that there was no comprehensive audio-visual information on cancer and nutrition and so she decided to raise some money and produce a DVD herself.

Together with Penny Webb from the Rarer Cancers Forum Linda raised thousands of pounds and persuaded various cancer centres and charities into giving their advice and suggestions.

Herefordshire cancer patients Dr. Joan Davidson and Sandra Woodward took part in filmed interviews at the Cotswold Care Hospice. Joan had suffered eating problems due to radiotherapy treatment and Sandra had found difficulty in

preventing further weight loss after surgery and during chemotherapy.

They travelled to the Cotswold Care Hospice for the filming and together with four patients from London did lengthy interviews talking about their experiences with finding advice about nutrition while suffering from the cancer or the treatments. They are looking forward to seeing the DVD launched later on this year. There will be two DVD's produced from the interviews. One will be aimed at training professionals in the field of cancer. The other will be for patients. Both DVD's will contain general information on nutrition, tips on how to make nutritional drinks more palatable, the best types of food to eat and sections on difficulty with eating, nausea, losing weight, gaining weight, constipation and diarrhoea. A Ready, Steady, Cook filming session took place and was filmed for the DVD.

Linda plans that the DVD will be sent to Cancer Centres around the country. It will be made available to Cancer Information Centres, hospitals and hospices and the Centres where oncology staff are trained. It will of course be available to patients to borrow from their cancer centre.

Joan and Sandra are enthusiastic about the project and the part they played in it. They hope that they will be able to attend an event to launch the DVD's soon.



None of the charities or 32 Cancer Networks throughout the UK have produced a video or DVD. Patients have identified the need, raised the capital necessary and done a professional job which will benefit cancer patients throughout the UK.



tips on how to make nutritional drinks more palatable, the best types of food to eat and sections on difficulty with eating, nausea, losing weight, gaining weight, constipation and diarrhoea.

# Questioning attitudes...

Are you a 'person centred' or 'system-centred' organisation?

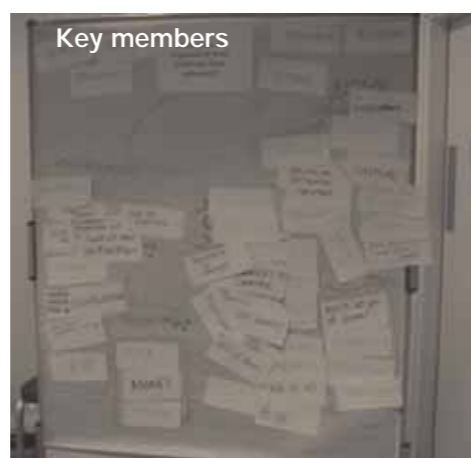
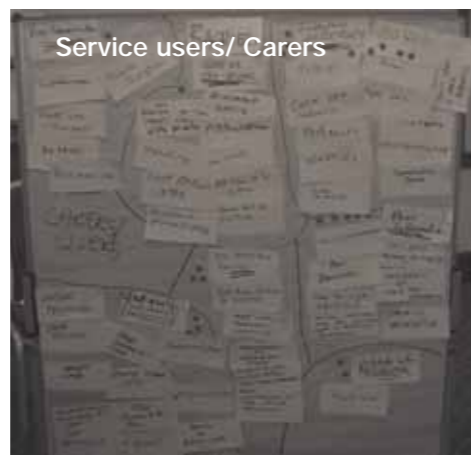
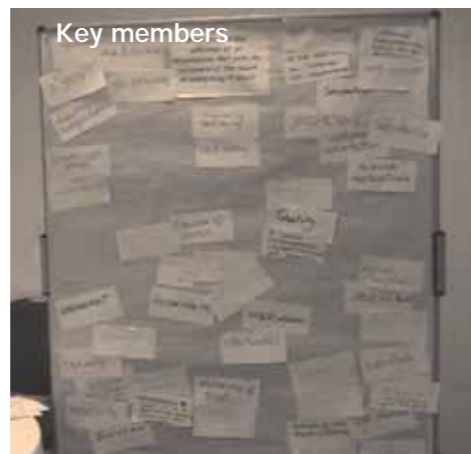
That was one of the questions being asked at the ADASS Workshop in Worcester July 2007. The workshop run in partnership with the Regional Network for Involvement and Participation was a gathering of directors, managers and service users from all parts of the West Midlands. People from all walks of life came together to talk and be involved in exercises around person centred approaches to the way services are delivered.

The day started with a presentation from CSIP (Care Services Improvement Partnership) which challenged the established model of change in services by putting the service user at the top feeding down through involvement and participation to Councils and service providers. The aim of this being an organisation that listens to what service users need and produces care and markets for this care around 'their' needs. Then followed a discussion with service users about what an individualised budget has meant to them. They spoke of how they are cared for and how it has given them the confidence and independence to break free from their condition and start living their life how they want.

The main consultation exercise was done in groups and discussed both the advantages of putting the service user in charge and the barriers that prevent this. The aim was to get organisations thinking about what they could do to make this a reality and the advantages of doing so.

Groups were split into service users and key members of organisations and the first question asked was "What are the key outcomes of an organisation that puts customers at the heart of everything it does?"

The responses were collated and stuck on to boards and below are two examples of some of the issues raised by key members, service users and carers.



The responses were grouped and the next question asked "What stops an organisation from achieving these outcomes?"

After this discussion the groups were then asked to think about action plans for the future to address the common themes identified.

The close of the day showcased some more service users. They told their stories though video or in person about how their personalised care has made a positive difference to their lives.

The day showed that putting the person at the centre of their care and allowing for their input in how it is delivered can make a real change to their lives, independence and well being. It is hoped that everyone who attended will take back what was said and start to think about overcoming barriers and making a real start towards change.

Are you a mental health service user or a carer of someone who is?

Do you want to have more influence over how local services are planned and delivered?

Do you like to have a say in how services are delivered in Herefordshire?

Herefordshire Users' Group) and the service users are working with Mental Health professionals to help shape the way services are delivered. Alison MacMahon from the service users' group of service users and carers has been involved in shaping the way services are delivered in Herefordshire.

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If you'd like more information by email contact Helen Lee on 01432 262016 or email: helen.lee@herefordpct.nhs.uk

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## How people are influencing intermediate care services in Herefordshire

Firstly, what do we mean by intermediate care? It's a range of services to promote faster recovery from illness, prevent unnecessary acute hospital admission, support timely discharge and maximise independence in daily life.

Hillside is a residential intermediate care centre in Hereford that opened in 2003, jointly funded by the Primary Care Trust and Herefordshire Council. Most patients come straight from hospital and spend a few days or weeks at Hillside re-gaining independence skills before returning home.

For the last couple of years the Involving People Team has run a monthly discussion group with patients to listen to their views and ideas about the service they are receiving. We talk about the staff, building, food, therapy, social activities, discharge planning ... lots of things. And all comments are anonymous but are fed into the Hillside Management Group meetings so that change happens and the service improves. Some examples of change that have been initiated by patients include:

- a daily delivery of newspapers
- a library with many books in large print
- a review of the patient information pack leading to a decision to rewrite it and make it more patient-friendly
- more social activities

Alf, a recent patient at Hillside, said of the service he received "It was brilliant, excellent I couldn't better them. I came from the County Hospital for rehabilitation care to Hillside for 1 week. The staff were very, very good, they encouraged me to do exercise which helped to a speedy recovery."

There is always much praise for Hillside, but it is providing an even better service today than 2 years ago, simply because the people who use it have the opportunity to tell us what works and what could be better. Very importantly, we listen and then act on what we are told by patients. And if something is not possible we explain why not.

Helen Lee