



# BRIGHT IDEAS



May  
2006

Physical Disability User Group

Inside this  
issue:

## Welcome to the Spring Edition of Bright Ideas. User Involvement

The PDUG is there to try and ensure Users can have their say in a safe environment. If you feel you wish to become involved please come along to our meetings. The dates are on the back page and travelling expenses are paid on the day. You will receive a warm welcome and be in the company of people who help to support each other.

to implementing the national Service Framework for long term neurological conditions.

The pages with the questionnaire on are in the middle to enable them be extracted from the newsletter more easily.

There is a pre addressed envelope included which requires no stamp.

## Let your wishes be known.

Without obtaining feedback from Users service providers are in the dark. Please ensure your views are made known. Fill in the questionnaire

## National Service Framework For Long Term Neurological Conditions

On page 5 there are details of a conference being held relating to the above. The PDUG will be represented at this conference and if any one else wishes to go please let us know and we will do our best to try and make it possible. I apologise for the short notice but please do let me know if you wish to go. The PDUG will ensure no one is out of pocket if they wish to attend.

## Priority for the NSF

On pages 7,8 you will find a questionnaire which enables you to comment on what you believe should come first when it comes



On page 5 you will find an article extracted from the Chronicle and Echo relating to the threatened closure of the Day Hospice at Cynthia Spencer. Can it accommodate many wheelchairs?

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## Independent Patient and Public Involvement Forums

In 2006 there are going to be a lot of changes in your local NHS. The following meeting dates give you an opportunity to comment how well your services work for YOU and what you feel could be done to make them better.

Remember PPI Forums are groups of volunteers who are backed by law to allow them to make a real difference and exist to represent the views of people from all walks of life.

GET INVOLVED AND HELP MAKE A REAL DIFFERENCE

Call Rachael or Sarah on 01933 271 300 or email [northants@patientsforum.org](mailto:northants@patientsforum.org)

### PPI Forum dates for Daventry and South Northants

**Friday 26 May (in public)**  
Wednesday 21 June

Public meetings 10am-12pm

### RULES

Meetings not held in public scheduled for 6.30 pm. Venues for these meetings will be confirmed on a month by month basis. Agendas will be sent out a minimum of 7 days prior to the meeting. Members of the public will only be invited to those meetings being held in public. Permission to attend non-public meetings as an observer may also be given following a specific request to the relevant forum.

### PPI Forum for Kettering General Hospital.

Tuesday 13 June

**Tuesday 11 July (in public)**

Tuesday 8 August

**Tuesday 12 September (in public)**

Tuesday 10 October

**Tuesday 14 November (in public)**

Tuesday 12 December

All meetings held between 7-9 pm. Same rules apply.

### PPI Forum for Northamptonshire Heartlands

Thursday 15 June

**Thursday 20 July**

Thursday 17 August

**Thursday 21 September**

Thursday 19 October

**Thursday 16 November**

Thursday 21 December

All meetings will be held between 1.30– 4-30 pm same rules apply. Public meeting in bold

### PPI Forum for Northampton General Hospital

Thursday 8 June

**Thursday 13 July**

Thursday 10 August

**Thursday 14 September**

Thursday 12 October

**Thursday 9 November**

Thursday 14 December.

All meetings will be held between 10 am– 12 pm. Same rules apply. Bold in public

Anyone interested in being involved in the Forum future work on issues related to carers or people with chronic long term illness is requested to phone Rachel Heaver on 01933 271300. Alternatively email [r.heaver@carersfederation.co.uk](mailto:r.heaver@carersfederation.co.uk).

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### **BT's Age and Disability team.**

The above team aim is to offer communication advice and support which is relevant to health care professionals, independent living specialists, and members of caring organisations and associated advice centres. All the latest information and offers can be viewed online at

[Www.btplc.com/age\\_disabilty](http://www.btplc.com/age_disabilty).

The mission of the above team is to drive disability issues deep into the operations of BT they aim to do this by

- Providing practical, day to day assistance for disabled people.
- Improving BT's product and service portfolio
- Research and development
- Consultation with disabled people and their representatives.
- Understanding and influencing legislation and regulation
- Raising awareness of disability issues
- Enhancing BT's reputation in the disability arena.

If you would like to be kept up to date with the ever changing amount of new technology you can be added to their database. If then any new information is considered beneficial to clients you will be sent up to date information usually by Email

[Www.btplc.com/age\\_disabilty](http://www.btplc.com/age_disabilty).

Email [disabilty@bt.com](mailto:disabilty@bt.com)

or phone 0845 6020191

### **Carers Urged to Act on Pension Rights.**

It is important that carers are aware of their entitlements and take the steps to

receive the maximum benefit. The reforms which the Government has introduced ensure that carers and people with long term illness can benefit from building a larger pension. Many carers and parents will receive their additional State Pension automatically. However, it is still important for people to make sure this is the case for them. Unpaid carers in particular may need to take action and apply for Home Responsibilities Protection to make sure they don't miss out.

To receive a copy of the information leaflet call 0845 60 60 265. Alternatively contact Jobcentre Plus Offices and local pension centres. It can also be downloaded from [www.the.pensionservice.gov.uk](http://www.the.pensionservice.gov.uk).

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### **Trivia**

A husband and wife are getting ready for bed. The wife is standing in front of a full-length mirror taking a hard look at herself.

"You know, dear," she says, "I look in the mirror, and I see an old woman. My face is all wrinkled, my bosom is barely above my waist, and my bottom is hanging out a mile. I've got fat legs, and my arms are all flabby." She turns to her husband and says, "Tell me something positive to make me feel better about myself."

He studies hard for a moment thinking about it and then says in a soft, thoughtful voice, "Well, there's nothing wrong with your eyesight."

Services for the husband will be held Saturday morning at 10:30 at St. Anselm's Memorial Chapel.

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## Article From Chronicle & Echo

THE future of Cynthia Spencer Day Hospice, reopened after a £1m upgrade only 10 weeks ago, was in doubt last night after talks were held about shutting it as a cost-cutting measure.

A Chronicle & Echo-backed appeal in 2004 raised a massive £1.5million for the £9.7million redevelopment of the Kettering Road hospice, which was completed at the end of last year. The day unit, caring for 50 people a week, was revamped as part of the project.

Daventry and South Northamptonshire Primary Care Trust (PCT) estimated the cost of the day hospice at 10 percent of the total development.

Management of the PCT, which runs the hospice, held a meeting yesterday afternoon to discuss the future of the facility.

Simon Schanschieff, chairman of the PCT said the day hospice was not being used as much as it used to be. He said: "They are having talks about closing it. They are reviewing patients there to see if they require the service. "I would be very surprised if it didn't shut.

"It is a shame. With finances being tight we have to make sure we are using facilities and staff to the full."

There has been a day hospice at the site for about 30 years and when it was first opened out patients used it every day of the week.

It is thought care at home by specialist nurses like those funded by Marie Curie Cancer Care has led the need for a day hospice to dwindle.

Mr Schanschieff added: "It is still very sad that we can't even keep it open two days a week."

Among the points discussed yesterday was how to provide care for the remaining out patients who still use the facility. A volunteer at the hospice, who asked not to be named, said: "We are all very angry and confused.

"It was only opened a few months ago. "The staff were told three weeks ago, the volunteers were told last week and now they are going to tell the patients. "I feel so bad for the patients. This is just awful. There must be some way to save this.

The hospice was officially reopened by Earl Spencer in February this year. It provides 20 beds for palliative care, including eight single-bed rooms. The day hospice provides a much-needed rest for carers and provides patients with the opportunity to mix with other people and visit a different environment.

alison.curtis@northantsnews.co.uk

09 May 2006



## **National Service Framework conference**

### Help Inform Priorities For Implementation

Primary Care Trusts, Social Services and the Strategic Health Authority for Leicestershire, Northamptonshire and Rutland are planning a stakeholder conference to help inform priorities for implementing the Department of Health National Service Framework for Long Term Conditions (NSF).

The conference will be held on 26<sup>th</sup> May 2006, from 10am to 3.30pm at Hothorpe Hall, Theddingworth, Near Market Harborough in Leicestershire

The aim is to consider the NSF quality requirements from a user and carer point of view. In addition to people with different neurological conditions and carers, services, professionals and agencies will be involved in the conference. There will be an exhibition with stands from services, voluntary agencies and sponsors.

For further information about the conference, sponsoring this event and display's contact the conference secretary Donna Phillips at:

Melton Rutland and Harborough Primary  
Care Trust  
PERA Innovation Park  
Nottingham Rd  
Melton  
Leicestershire  
LE13 ORH

**Telephone 01664 855507**

Email [donna.phillips@mrhpct.nhs.uk](mailto:donna.phillips@mrhpct.nhs.uk)

## **Other opportunity to have you're say.**

If you do not wish or cannot attend the conference (spaces are limited) please ensure your view is heard by filling out the questionnaire on pages 7 and 8. A fuller explanation of the quality requirements is given on page 9.

## **WHAT IS QUALITY?**

The word quality can mean many different things to different people. The word quality is defined as -

*The degree of excellence of a thing* , this can be either good or bad in quality.

### **Quality Control in manufacturing.**

In order to judge quality objectively quality standards are used extensively in the manufacturing environment by testing a sample of the **output** against the specification. Such a standard might be that the dimensions of a machined component are within a certain tolerance. Now I am sure you will agree anyone given the necessary training can judge quality standards in the manufacturing environment.

### **Quality standards in service industries.**

In the service industries, be they either in the private or public sector, in order to measure the output of a service you have had to go through the system. The point again highlights the fact only the User of a service can judge the **output** of a service as it is only him or her who has gone through the system.

### **Customers perspective is paramount.**

Without the Users perspectives of a service or goods quality assertions are open to miss representation due to vested interests.

### From Bill Broadribb

#### Free Services from Gas and Electricity Suppliers: -

Persons of pensionable age or are disabled may be entitled to free services.

These include: -

Unique password scheme

Bill nomination scheme

Energy bills in large print, audio or Braille

Annual safety check for gas appliances

Special controls and adaptors

For more information contact Energywatch on 0845 906 0708 or visit their website at [www.energywatch.org.uk](http://www.energywatch.org.uk)

#### Dogs for the Disabled: -

This is the charity that provides trained dogs to help disabled people. Did you know that they do not receive any government funding? They rely on donation to run all their schemes. They are looking for people to sponsor one of their puppies, which will be trained to help someone. They are asking for a regular gift of £3 a month.

For more information ring 08700 77 66 00 or email [info@dogsforthedisabled.org](mailto:info@dogsforthedisabled.org) or visit their website [www.dogsforthedisabled.org](http://www.dogsforthedisabled.org)

#### Ryder- Cheshire Volunteers (RCV): -

For 20 years dedicated staff have been helping disabled people to take part in leisure and learning activities.

Each person can choose his or her own interest. RCV may arrange for a volunteer to visit them at home or take them out. Others are helped to independently join a local club, group or college.

For further information ring 01926 485446 or email [info@rydercheshire.co.uk](mailto:info@rydercheshire.co.uk)

### By Peter Rayner

#### *What Is A Dream*

*A dream can be a life which a person lives  
in their sleep,*

*A dream can be a hope which you have  
hidden down deep,*

*A dream can be a wish which we all try to  
keep,*

*Or it can be desire which we sow and then  
reap,*

*But to every person a dream is a different  
thing,*

*And who knows if we hold on to them  
what joy a dream may bring*

CHOCOLATE

CHOCOLATE we all love CHOCOLATE

Whatever our characteristics  
Whether we are MALTESERS  
Or SMARTIES.

You may be the sort of HEROE  
Who would like to BREAK AWAY  
And leave this planet in an AEROplane  
Cruise through the MILKY WAY  
Explore the GALAXY  
Or visit MARS

On the other hand  
You may wish to stay at home  
On your QUALITY STREET  
In YORKIE

You may own a pet KITty KAT  
Or wish to own a LION

Some people are "well 'ard"  
And CRUNCHIE  
Or you may be a bit of a FLAKE  
Some people when chaos ensues  
May just let it ROLLO ver  
And ignore it  
While others may imitate the  
Willy Wonka EXPLODER

Some people have cheeks  
That reflect ROSES  
Others are more of a  
(TERRY'S CHOCOLATE) ORANGE hue  
but it doesn't really matter  
what we're like  
because we all love  
CHOCOLATE

## Questionnaire (for long term neurological conditions)

### Q1 Where do you live ?

- Leicester City
- Leicestershire
- Rutland
- Northamptonshire

### Q2 Are You

- A person with a neurological condition
- A relative or carer
- Responding for support or voluntary group
- Professional/Statutory Agency

### Q3 . If you have a neurological condition what is the condition ?

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### Q4. Based on your experience please tell us which National Service Framework requirements you think local services are achieving. ( See page 9 for the list of requirements) You may want to give an example.

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### Q5. If you think there are gaps in the services required in the National Service Framework please tell us what they are.

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**Q6. Below is a list of the National Service Framework quality requirements. In order of priority ( 1 being the highest) which 3 requirements do you think should be progressed over the next few years.**

- A person centered service
- Early recognition followed by prompt diagnosis and treatment
- Emergency and acute management
- Community rehabilitation and support
- Vocational rehabilitation
- Equipment and accommodation
- Personal and support
- Palliative care
- Support for family and carers
- Care during admission to hospital or other health and social care settings

**Q7 What aspects of the service would you like to see improved for your choices above?**

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Please send completed questionnaire in the pre addressed free post envelope included with the newsletter. Thank you.

## **Explanation of Quality Requirements.**

### **1: A person-centred service**

This is a main theme that runs throughout the NSF. All people with long-term neurological conditions are offered a full assessment of their health and social care needs. In addition, they are to be offered information and education about their condition; the chance to make decisions about their treatment; and to be involved in writing a plan about how their needs will be met (a care plan).

### **2: Early recognition followed by prompt diagnosis and treatment**

Anyone suspected of having a long-term neurological condition is to quickly see a doctor or other professional, with expert knowledge of that condition. They should have tests, be given a diagnosis and have any treatment they need. This should be as close to home as possible. This is so that a correct diagnosis and appropriate treatment happens as soon as possible.

### **3: Emergency and acute management**

Anyone admitted to hospital for a neurosurgical or neurological emergency is assessed and treated by professionals with the right skills and experience who have access to the right facilities and equipment.

### **4: Early and specialist rehabilitation**

Anyone with a long-term neurological condition who would benefit from rehabilitation is to receive timely, high quality rehabilitation services in hospital or other specialist settings when they need them. When ready, they are to receive the support they need to return home for more community rehabilitation and support.

### **5: Community rehabilitation and support**

People with long-term neurological conditions living at home are to receive a full range of rehabilitation, advice and support to meet their continuing and changing needs. This is to increase their independence and help them to live as they wish.

### **6: Vocational rehabilitation**

People with long-term neurological conditions are to have appropriate support to help them find or regain employment, to remain in work or to pursue educational opportunities.

### **7: Equipment and accommodation**

People with long-term neurological conditions are to have the equipment they need (such as wheelchairs), within an appropriate time frame and to have adaptations made to their homes as and when needed, to support them to live independently; help them with their care; maintain their health; and improve their quality of life.

### **8: Personal care and support**

Health and social care services are to work together to ensure that people with long-term neurological conditions are given the care and support they need to live independently in their own homes wherever possible.

### **9: Palliative care**

People with long-term neurological conditions nearing the end of their life are to have access to a range of palliative care services as and when they need them, to control symptoms and offer pain relief, and to meet any personal needs they may have.

### **10: Support for family and carers**

All carers of people with long-term neurological conditions are to receive appropriate support and services which recognise their needs as a carer and as an individual in their own right.

### **11: Care during admission to hospital or other health and social care settings**

All people with long-term neurological conditions are to have their specific neurological needs met when they are receiving care for any other reason in any health or social care setting.

# USEFUL CONTACTS

## **Volunteer Centre**

01832 733336  
Flexicare Manager

## **PALS**

Patient Advice and Liaison Service  
Heartlands PCT  
01536 494233

## **Care & Repair, Kettering**

Address Bowling Green Road Kettering  
Northants NN15 7QX

Contact Name Malcolm Coe

Telephone **01536 534211**

E-mail [malcolmcoe@kettering.gov.uk](mailto:malcolmcoe@kettering.gov.uk)

Care & Repair offers practical advice and guidance to elderly or disabled homeowners who need help in organising repairs, renovations, adaptations, grants, welfare benefits and insurance claims to their own homes.

## **Kettering Shop mobility**

Wadcroft Car Park Commercial Road Kettering Northants NN16 8TH  
Telephone **01536 412886**

## **'Disability Link'**

Isebrook Hospital Irthlingborough Road  
Wellingborough Northants NN8 1LP Telephone **01536 494250** or Text phone. **01536 49425** Fax **01536 494251**

Aims to support disabled people from 16 years upwards, with a physical impairment, their Carers and families to achieve maximum independence, choice and control in their lives.

## **Disability Employment Advisor**

Mick Leonard 01604 446157

## **Incapacity Benefit Advisor**

Clair Mackintosh/Gill Whitlock  
01604 446215  
Marie Yates

## **Disability Sports Development Manager**

Northamptonshire Sport  
John Dryden House  
8-10 The Lakes  
Northampton  
NN4 7DD  
Phone : 01604 237940  
Mobile : 07709 399321

## **East Midlands ICAS**

Independent Complaints Advocacy Service.

If you, or someone you care about, has a complaint about any aspect of NHS care or treatment, ICAS can offer information, advice and support.

ICAS is:

Confidential

Free of Charge

Independent of the NHS.

Call 0845 650 0088

EMAIL [ICAS@carersfederation.co.uk](mailto:ICAS@carersfederation.co.uk)

## **Enterprise Training Project.**

Courses for carers and people with physical disabilities. 01604 603045

## **Community Resource Team**

Aims to reduce social isolation  
01604 665920

## **Ryder-Cheshire Volunteers South**

**Northants project** (Leisure and learning interests for people with a disability)

Tele 01280 704736 or visit

[www.rydercheshire.co.uk](http://www.rydercheshire.co.uk)

## **Take 6**

Taxis for disabled people

01604 764678

**REMAP****Custom made aids for people with disabilities**

Telephone: 0845 1300456

website: [www.remap.org.uk](http://www.remap.org.uk)**HOLIDAY CARE****Holiday and Travel Information for Disabled People**

Phone: 01293 774535

Website: [www.holidaycare.org.uk](http://www.holidaycare.org.uk)Email: [holiday.care@virgin.net](mailto:holiday.care@virgin.net)**Riding for the Disabled**

Head office 02476 696510

**Leonard Cheshire 01295 811398**

(Volunteers for assisting disabled to undertake their hobbies)

Information on **country parks** and facilities available for the disabled at these venues contact **01604 237227**

**Transport**Northampton Door to Door Service  
01604 611214**Equipment services**Community OT Therapy service  
01604 658411

Occupational therapy wheelchair specialist

01604 658423 .

**Northampton Carers Centre**

01604 232500

**Health advice. NHS direct (24hrs)**

0845 4647

**Age Concern**

01604 611200

**Benefits Agency**

01604 446100

**Citizens Advice Bureau**

01604 636000

**Welfare Rights**

01604 636112

**Sailability (Pitsford water)**

079 525 793 80

[www.northamptonsailability.org.uk](http://www.northamptonsailability.org.uk)**Ability Northants**

01604 624088

**Care & Repair Northampton**

01604 588604

**Care and Repair Daventry**

01327 302322

**Carers response team**

Northampton 01604 611200

Daventry/South Northants 01327 701681

Kettering/North Northants 01536 312412

**Carers signposting**

01604 624088

[Www.caringnorthants.org.uk](http://Www.caringnorthants.org.uk)**Two Shires Ambulance Service**

Patient transport liaison officers

Kettering 01536 492344

Northampton 01604 545858

Peterborough 01733 262692

## Physical Disability User Group

To contact the User Group & Bright Ideas

Tel 01604 406710

Email

iantopp@btopenworld.com

9 Holman Close

Weston Favell

Northants

NN3 2TF

## Ability Northants

DISABILITY INFORMATION

SERVICE.

13 Hazelwood Road Northampton

NN1 1LG

**TeleTel: 01604 624088**

## User Group Meetings.

User Group meetings

June 30th Friday 2006

July 25th Tue 2006

August 25th Friday 2006

Sept 29th Friday 2006

Oct 27th Friday 2006

1.30 pm Tea/Coffee

2.00 pm meeting starts

4.00 pm approx finish

At the

**DODDRIDGE CENTRE.**

**109 Saint James road**

**Northampton**

Email: [louise.shaw@abilitynorthants.org.uk](mailto:louise.shaw@abilitynorthants.org.uk)



If you are still unsure where to go for the User Group meetings please ring 01604 406710