# Carers News



## Welcome & Contents

#### Carers News is back!

Hello and welcome to our new re-energised publication as part of the brand new Cornwall Carers Service.

In these pages we give you an overview of the new service and cover some important news stories. We examine the new welfare reform proposals and how they may impact on relevant benefits, and on a lighter note, suggest some attractions worth a visit this summer that offer concessions to carers and / or the person you care for.

Please remember, Carers News is your magazine and we welcome any articles, letters, poems or photos you may like to share. We would also love to hear from you if you would like to join a steering group to guide future editions.

Have a great summer.

#### The Carers News team

#### Please send your letters and articles to:

Carers News, Disability Cornwall, Units 1G/H Guildford Road Industrial Estate, Hayle, Cornwall TR27 4QZ. T: 01736 756655

1. 01/30 /30033

E: carersnews@disabilitycornwall.org.uk

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members or sponsors.

# The new Carers Service for Cornwall



Cornwall Rural Community Council (CRCC) is working in partnership with Age Concern Cornwall, Carers Rights and Disability Cornwall, to create the long awaited and much needed Cornwall Carers Service (CCS).

The CCS is a new and comprehensive service offering a wide range of information, support and services to carers, concerned family members, friends and those working to improve the quality of their lives. With just one call to the dedicated helpline, we can offer you the support needed in your caring role.

The CCS aims to identify hidden carers, while at the same time, support the 55,000 people in Cornwall who identified themselves as carers in the 2001 census.

Commissioned by Cornwall Council's Directorate of Adult Care & Support, the CCS will also provide regular forum and training events, an informative website and a complement of 20 staff across the county.

# So who will do what?



# Cornwall Rural Community Council

Having provided support to carers for the last 18 years, CRCC is well placed to lead and deliver the Cornwall Carers Service, recognising as it does, the wide range of issues and needs carers face, in addition to the information, support and services that will help them to continue caring.

CRCC will be developing a dedicated website to go live in October, increasing its current complement of carer support workers, to incorporate specialist workers for carers of adults with learning difficulties, mental health issues or dementia, and provide specific workers to support young adult carers and people from black & ethnic minority backgrounds.



#### **Age Concern Cornwall**

Will be running the Carers Helpline, operational from 16 June. Two dedicated advisers will work alongside existing Age Concern staff so carers can expect an experienced team who will be available from 8am–6pm Monday to Friday to respond to queries, take referrals and offer support. Information will be provided on an answerphone at other times regarding out of hour's services.



#### **Carers Rights**

Will facilitate forum events across the county overseen by a dedicated forum & events coordinator. These regular

events are designed to provide a 'voice' for carers and related issues.

Carers Rights will also offer free expert training, open to all carers past and present, who would like to help others access their rights. Among the trainers is a previous adviser on carers' issues to the last government. Training to be covered includes community care law, what to do when something goes wrong, wills & trusts and continuing care (free funding for long term care due to health needs). Please contact Celia Blake for further information.

**T:** 01872 264057

E: celia.blake@carersrights.org.uk



#### **Disability Cornwall**

Will publish three editions of Carers News per year. This A5 magazine will contain news articles, helpful information and human interest stories. Disability Cornwall would like to facilitate a group of individual carers and support workers to help guide the publication. Feedback is always welcome, especially contributions from carers for future editions.

Disability Cornwall will also provide a 'Continuing Support Service' to help people whose caring responsibilities have ended, due to bereavement or other permanent care arrangements being put into place. The service is dedicated to assist the person concerned readjust to the next phase of their lives.

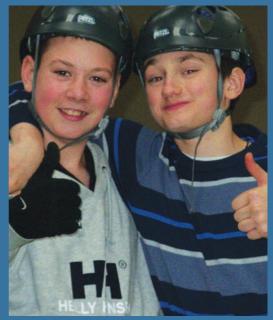
The four organisations comprising the Cornwall Carers Service aim to meet the needs of all carers in Cornwall. The services provided will have carers themselves at the heart of their development, from working with the Carers Partnership Board, to consultations and having people concerned on working groups to ensure the service is 'getting it right'.

# Sam's Story

In school, Sam found it hard to concentrate in lessons because he was often worrying about his mum. He knew he was behind in some subjects and this made him worry even more. He thought the teachers would think he wasn't interested or bothered about his school work, but sometimes school work just had to come second.

After school, he couldn't join in football training or hang out with his mates, because he had to rush to pick up his sister and then get home to make sure his mum was OK. As well as getting his homework done, Sam had to prepare dinner, make sure the house was clean and tidy and help his sister get ready for bed. Sometimes he wouldn't get to bed until midnight and would be so tired he often found it hard to stay awake the next day at school.

Sam is 14 years old and dreams of becoming a doctor. He lives with his eight-year-old sister Susannah and his mum. His mum has diabetes and finds. walking difficult. Because of this, she spends a lot of time indoors and relies on Sam to help her and Susannah.





Above & overleaf, some of Cornwall's young carers out and about

Sam's situation continued like this for many months and he had no hope of things getting better, he thought it would just carry on getting worse. But one afternoon after a difficult day at school, Sam plucked up the courage to tell a teacher he trusted about what was going on at home. He managed to speak to the teacher in private and she was really understanding and also knew a bit about young carers. She arranged for some extra help for Sam and she talked to a support worker who helped Sam's mum.

Now, the family have support. Sam's mum has an emergency alarm fitted in her house so she can call for help if she needs it. That's helped Sam to stop worrying about her when he's out of the house. The support worker also comes

during the week to help Sam's mum with cooking and cleaning so Sam is doing less of that now.

At school, things have changed too. Sam is allowed to use the school secretary's phone to call his mum at break times and check that she's OK. He's met other young carers in his school and they meet up during lunchtime once a week. His school has a young carer's notice board. He's having extra help in subjects he finds hard, nearly all his grades have improved and his dream of becoming a doctor feels more possible now.

If you are a young carer there is help and support available. Please call the Cornwall Carers Service helpline.



Cornwall Carers Service Helpline

# Families at breaking point

VOLUME

Carers UK Support Families: Don't Cut Care campaign, asks local authorities to prioritise care in the current bleak economic environment. It calls for a sustainable solution to the funding of social care – otherwise they say, coupled with cuts, families will be further driven to breaking point.

Riven Vincent's cry of frustration she could no longer cope with the exhausting demands of caring for her severely disabled daughter, Celyn, echoed way beyond the internet talk board where she posted her heartbreaking confession, and planted the issue of social care spending cuts on the front pages of national newspapers.

Her revelation that she had, in desperation, asked social services to take her daughter into care because she had been told they couldn't extend the six hours of respite care she currently received would, ordinarily, have caused few ripples. But she had already become a symbol of Prime Minister David Cameron's commitment to protecting society's most vulnerable citizens. The Prime Minister, whose late son Ivan, like Celyn, had cerebral palsy and severe epilepsy, had visited Riven and her daughter at home in Bristol during the general election campaign.

He assured her if he won he would not do anything to harm disabled children.

That promise has now begun to look a little threadbare. Riven said: "I had hoped after David Cameron came to visit he would have done more to protect families like ours."

The Prime Minister replied he was going to look 'closely' at her case. But the prospects for disabled people, their families and carers looks increasingly bleak as local authorities struggle with government imposed budget reductions of up to 30%.

Carers organisations are receiving calls from people feeling pushed to breaking point and having to battle for every bit of support they receive. At the same time, it's these very families that save the state billions every year with the free health & social care support they provide.

Carers UK wanted people to tell them what it's like to be caring for somebody in Britain today and appealed for carers to complete a survey, which closed in March. Results of 'State of Caring' will be published later in the year.

T: 0808 8087777 (Carers UK advice line is open from 10am-12 & 2-4pm Wednesdays & Fridays) www.carersuk.org



# Carer emergency card scheme

Would you like a safety net to support you in your caring role?

- Do you worry about what would happen to the person you care for if you were prevented from getting home because of an unforeseen emergency?
- Do you avoid going places because of fear that something may happen to you and the person you care for would suffer?
- If an unplanned incident should happen who would know your contingency plan?

The Carers Emergency Card Scheme is designed to provide you with peace of mind that your contingencies should any unplanned emergency occur to you be accessible to all.

#### What do I need to do?

Complete a carers emergency plan and submit it to the carers emergency card Administrator who will enter your plan onto lifeline and issue you two cards with a unique ID number and lifeline telephone number.

When this unique ID number is quoted to lifeline they will call up your plan and contact people you have requested in the case of an emergency.

This service can support the person you care for, for **up to 48 hours.** 

For more information please contact the Emergency Card Administrator on: **01872 324369**.

If you would like this information in another format or language please contact:

Cornwall Council, County Hall, Treyew Road Truro TR1 3AY

Telephone: 0300 1234 100
Email: enquiries@cornwall.gov.uk
www.cornwall.gov.uk

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## What are you doing this summer?



**Cinema Exhibitors' Association Card:** A national card scheme to verify the holder is entitled to one free ticket for a person accompanying them to the cinema. To apply, the person you care for will need to submit proof to show he or she is registered blind or in receipt of Disability Living or Attendance Allowance.



**Flambards:** The West Country's leading family attraction with spectacular rides in the Big Ride Zone, as well as some award-winning and unique exhibitions, including the Victorian Village and Britain in the Blitz.



**Newquay Zoo:** Experience the world's wildlife with Cornwall's award winning zoo, part of the Whitely Wildlife Conservation Trust. Set amid sub-tropical gardens and home to over 130 species, there is plenty to entertain the family including keeper talks, animal encounters and feeding times throughout the day.



**Blue Reef Aquarium:** Be amazed by local marine wildlife not only from Cornwall but also hundreds of tropical species. The gigantic ocean display features an underwater tunnel to enable you to appreciate the huge range of sea life from lobsters and sharks to seahorses.



**Crealy:** Experience Cornwall's legendary attractions, combining magic and myths, wild rides and exciting adventures, while getting nose to nose with nature and animals. Scramble around the Dragon Kingdom with super slides, ball pools and mazes and just for the little ones, explore the toddler zone with soft play, slides and shapes.



**Bodmin and Wenford Railway:** Discover the excitement and nostalgia of steam travel with a journey back in time on the Bodmin & Wenford Railway, Cornwall's only full size railway still operated by steam locomotives.



**National Seal Sanctuary:** Set in the picturesque Helford Estuary, this is a rescue, rehabilitation and release centre for seals. During most seasons, over 40 pups are rescued and cared for in a specially designed hospital and convalescence pools. Otters and penguins are among other animals for you to see.



**Playzone:** Fun for all the family as both kids and big kids can run riot at the Play Zone! Masses of safe indoor areas with endless things to do including an indoor adventure playground, laser tag arena, arcade, huge drop slide, and licenced bar & cafe.



**Ships & Castles:** One of Falmouth's premier attractions, the leisure pool provides daily fun for all the family throughout the year for visitors and residents alike. A fully accessible Changing Places facility has recently been installed.



**Paradise Park:** Cornwall's top wildlife sanctuary containing over 650 types of birds and lots of other wildlife including the Fun Farm with donkeys, goats and rabbits among the furry friends. The Jungle Barn indoor play centre offers huge slides and soft play areas beside a snack bar where daily papers are available.

#### Carer £14.75 saving £5.20 T: 0845 6018684 www.flambards.co.uk Disabled adult £10.45 saving 50p Trenance Gardens, Newquay TR27 2LZ Disabled child £7.70 saving 50p T: 0844 4742244 (local rate) Carers are free if with a disabled adult or child Towan Beach, Newquay TR27 1DU for whom the cost is £9 T: 01637 878134 www.bluereefaguarium.co.uk Price depends on your height! Carers are free and both disabled Wadebridge PL27 7RA adults and disabled children enjoy the concessionary price £11.45 T: 01841 540276 www.crealv.co.uk Disabled people travel half price on any branch line and Bodmin PL31 1AQ employed or voluntary carers are free, but not family members T: 0845 1259678 Type Talk: 1800 101 208 73555 www.bodminandwenfordrailwav.co.uk Carers are free if with a disabled adult or child Helston TR12 6UG for whom the cost is £13.28 T: 0871 4232110 www.sealsanctuary.co.uk Disabled child (3-18 yrs) £3.00 Carbis Bay, St Ives TR26 3HW saving just over half price Tel. 01736 799499 Adults and/or carers (18 yrs+) £1.50 www.theplayzone.co.uk

T: 0845 1231292

www.ceacard.co.uk

Helston TR13 0QA

Falmouth TR11 4NG

www.carrickleisureservices.org.uk

T: 01326 212129

Hayle TR27 4HB

T: 01736 753365

www.paradisepark.org.uk

Text phone: 0845 1231297

A passport-sized photo needs to be supplied with the application and

Evidence of disability benefits required including Carers Allowance to

receive a 'breeze card,' which entitles carers and disabled people to

discounted entry

Carer £10.50

Disabled adult (16 yrs+) £10.50

Disabled child (3-15 yrs) £7.95

All saving £2 on the standard prices

will appear on the actual card. A processing fee of £5.50 per card

must be sent at the same time

Disabled adult or child £9.75 saving £10.20

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## Know your rights

Since last October, millions of people caring for a disabled person gained new rights under the Equality Act 2010. Carers, already protected from discrimination or harassment if it occurred in the workplace, saw their rights extended and are now protected from any form of direct discrimination or harassment, which occurs because they happen to be caring for somebody.

As an example, Ms Battle has applied for a job which involves a lot of travelling. She has the best skills and experience, but the company knows Ms Battle cares for her disabled son and makes an assumption she couldn't manage because of this and so doesn't offer her the job. Under the new laws, this would be regarded as direct discrimination, because Ms Battle is associated with a disabled person and it's against the law to refuse to offer her a job for that reason.

The new law will also afford protection when, as a carer, you are shopping for goods, ask for or receive services, or when you use facilities such as public transport.

If you're caring for an elderly person, the Equality Act 2010 will only protect you at work, until additional parts of the law come into effect at a later date.

There have been many cases over the years where carers have been treated less favourably by employers, overlooked for promotion, or not allowed any form of flexibility. Around 3 million people currently juggle work with caring responsibilities and these rights could make a big difference. Employers who actively support carers better in the workplace have found real business benefits as a result. Not only have the lives of the carers improved, but the business has saved money and retained valuable staff.

The new rights protect carers where they are provided with a worse service than someone who isn't caring for a disabled person. In addition, it affords protection where carers are discouraged or prevented from using a service because they are caring for a disabled person.

For further guidance on the rights of carers under the Equality Act 2010 visit:

www.equalities.gov.uk/ staimm6geo/pdf/GEO\_ EqualityAct2010\_Carer\_acc.pdf

Or call the Cornwall helpline.

## Council faces High Court legal challenge

Blackburn Council are facing a High Court legal challenge following their decision to cut short breaks funding for over 20 disabled children.

The families concerned, who were told late last year the council was no longer going to support the service from this April, have instructed a law firm to take the case on their behalf as they believe the council has acted unfairly and unlawfully. Irwin Mitchell have secured a court order to ensure all the care packages remain in place until a decision is made by the court in late May, as Carers News goes to press.

Irwin Mitchell will argue the council's decision to cut costs due to reduced central funding is based on a false premise. Although 'ring fencing' is

coming to an end, the government has announced an allocation of £800m to English local authorities to ensure the continuation of short break services. It's also claimed the decision will represent an infringement of the families' human rights and is a breach of both the Equalities and Children's Acts.

Christine Lenehan of Every Disabled Child Matters said: "It's concerning that local authorities are cutting services without demonstrating how they will meet the needs of disabled children and their families through alternative provision. If Blacburn Council is found to have breached the law, it will set a precedent and act as a warning to other local authorities they could also face the risk of a legal challenge."

## Carers are watching

Carer Watch, a campaign group run by independent carers, hope the recognition that carers are unique within the benefit system, will be the start of a complete reform of carer benefits. Only then will the much needed support truly be in place.

There have been many campaigns over the years by various organisations all asking for the same – the reform of Carers Allowance – to remove the restrictions and increase the monetary

pittance that it currently is.

Therefore, while the decision to keep Carers Allowance separate from the proposed Universal Credit is welcome, Carer Watch say this is not the end but the start. They call on the government to make a statement explaining how they intend to reform the allowance and ensure carers finally receive the full recognition they deserve.

www.carerwatch.com

# Ask me what I can do

Are you happy? Imagine if, to be able to do the simplest things, from popping to the shops to showering, you had to answer 'no' to that question. Imagine if you had to emphasise this to strangers, who then wrote it down to copy and distribute to other strangers. This is what my teenage daughter had to do, time and again over the last few months. She is disabled and just turned 18. which means she has to be assessed for support by adult social care. 'Are you happy?' is one of the questions on the assessment forms and unless she repeatedly says 'no', she won't get any support.

Riven Vincent, made national headlines when she said she would be forced to put her daughter, who like mine has quadriplegic cerebral palsy, into care if the respite support she needs is not provided. 'We are crumbling' wrote Vincent, hoping that plea will make a difference. I have no doubt her family's daily life is a struggle as it is for every family with a disabled child, but I also sympathise on another level, I know the only way to get essential support is to do as she has done and portray a family on the edge.

It's obscene that families are forced to give such a bleak account of their lives. I've been asked by social workers if the additional care my eldest child needs means I neglect my two non-disabled, younger children. I refused to say it did, so we never had one hour or one penny of support from social care. We lived with that. But now my daughter has turned 18. she is entitled to support in her own right, and has a desire and a right to live an independent life, replacing my unpaid support with social care. But to get this she has to claim she is desperate, unhappy, 'crumbling'. She has to conform to the image of the thwarted disabled girl we have spent the last 18 years fighting. She has to openly declare her life is a tragedy.

The assessment is entirely based on what you can't do. In several interviews with social workers, each lasting over two hours, my daughter had to talk about her inability to wash, dress, walk, sit, and get in and out of bed. She has not been asked about her excellent AS grades, her shopping trips, or helping her siblings with their homework.



The first social worker who assessed her was a middle-aged man she had never met before. He arrived with a form and lots of boxes to tick. Much of my daughter's care is intimate. It was difficult for her to talk about this with a male stranger, but more difficult for the stranger himself, he was visibly embarrassed. "We don't need to talk about that," he muttered, flicking to the next page. But we do need to talk about it.

I've spent hours trying to make my daughter feel comfortable and confident in requesting the personal care most of us would balk at. Such honest conversations with carers need to be part of her life. The social worker made her feel as if she ought to hide it, so she stayed silent and it didn't go down on her form. As soon as the social worker left, my daughter burst into tears. Spending over two hours talking about the things you can't do is hard for anybody. In a world in which being proud, powerful and disabled means challenging every assumption made about you, this is particularly wounding.

I was so worried about the damage this had done, I asked our GP if my daughter could receive counseling to re-boost her self-esteem. Ironically, this counseling would be paid for by the same primary care trust fighting against her support costs. Perhaps, if they spent more money on care, they could spend less on counseling those who didn't get it.

There is another way. Instead of strangers with clipboards, the first stage in an assessment could be made by the disabled person themselves. My daughter could have been asked to keep a diary of what she did and what she needed help with. It needn't be written, it could be recorded or dictated. This would allow her to paint a rich portrait of her teenage life, which includes seeing 'The King's Speech' with friends as well as someone helping her on and off the toilet.

My daughter's life is not an unhappy one. It's as fraught and full as most 18-year olds, she just needs support with some everyday tasks many take for granted, sadly, what she can't take for granted is that she is going to get any.

Original source: The Guardian

## notice board

# Carers Week – the true face of carers – from 13 to 19 June 2011

Carers Week 2011 will be revealing the surprising stories behind the six million carers who save the country's economy £87bn every year. It will highlight and celebrate the incredible contribution carers make, sharing the challenges overcome as well as those still being faced. Nationally, there will be campaigns for greater support and recognition and informing carers who are unaware of the services and benefits they are entitled to.

Locally, Andrew George MP will attend a dedicated tea party for carers at Hanover Court in Penzance from 2–4pm on Friday 17 June. Further information on what is occurring in Cornwall to mark the week is available from the CRCC website and the Carers Helpline. www.cornwallrcc.org.uk/services/carers

## Carers Direct NHS choices

Available in 170 languages, this is a free, confidential, information and advice service for carers. The telephone line is open 8am–9pm Monday to Friday, and 11am–4pm at weekends. Calls are free from UK landlines and mobiles or you can request a free call back.

T: 0808 8020202 www.nhs.uk/CarersDirect/Pages/ CarersDirectHome.aspx



#### **Message in a bottle**

A free emergency information scheme to alert the emergency

services to important medical information and contact details, should an accident or sudden illness occur. You store the bottle in the fridge, with a completed form inside it containing your relevant medical information, then place one sticker inside your front door, so it's clearly visible and another goes on your fridge.

Contact DIAL T: 01736 759500 Or your local Lions Club or GP for a bottle in the fridge pack.

#### **CARERS UK Chat Forum**

A place where carers can share frustrations, concerns, advice and support. From finding a relaxing walk in



Bath to the impact of the spending cuts, there is a wide range of topics being discussed on the online forum.

www.carersuk.org/forum

#### **Carers World Radio**

Featuring the latest news and developments on topics relating to caring from around the world.



Carers World Radio has also pioneered innovative live broadcasts from events and conferences where carers at home are able to interact with presenters and the live audience via a chat room.

www.carersworldradio.com

# Colour Group still going strong

We are a group of carers for people with mental health problems. We have been together for six years and were started by Julia Rowlands, who has been a great inspiration to us and still keeps a motherly eye although she now lives far away in Kent!

The group meet weekly on Tuesdays at the Victim Support premises in Pool with the purpose of producing artwork. We tend to use oil pastels which result in bright pictures which we have successfully exhibited and sold. We use a standard size of paper and frame and this gives a pleasing coherence to our displays.

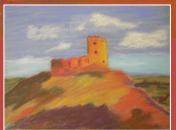
Our pictures are on display at the offices of both Victim Support and Disability Cornwall in Hayle, and also here in the magazine for Cornwall's carers. Although we mainly work with pastels we like to explore other media too and have worked with inks, water colours, felts and cut paper.

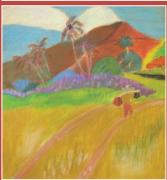
With the help of some young volunteers we even produced an animated film which was entered into the Cornwall Film Festival competition. We may not have won a prize but enjoyed watching the film at The Phoenix cinema in Falmouth.

We really want to expand the group and would love to welcome you. Please contact Julia Rowlands for further information.

T: 07778 162019

E: jdrowlands@yahoo.com









# Will my benefits change?

There are many changes and proposed alterations to the benefit system which are causing a great deal of confusion. Firstly and most important to note, is that Carer's Allowance is not directly affected by the changes. The Coalition Government appear to have recognised the unique position of carers within the benefit system, however, it's still worth checking how the proposed reforms may affect your other entitlements.

Carers, who also receive a means tested benefit such as Income Support, will find they will be transferred onto the new Universal Credit. This is to be introduced from 2013 onwards, as a replacement for the majority of means tested benefits and tax credits. Details of this are only gradually being released, but we will try to keep you informed as we learn more.

Currently the person you are caring for needs to be in receipt of either the middle rate of Disability Living Allowance (DLA) care component, or Attendance Allowance, before Carer's Allowance can be paid. At present, no changes to Attendance Allowance or DLA for children have been proposed.

However, adults currently on DLA will be reassessed for the new Personal Independence Payment from 2013 onwards. The majority of claimants will be asked to complete a new form and attend an appointment with a health professional to see if they qualify for the new benefit. Obviously failure to qualify for the new 'daily living component' of the Personal Independence Payment, will affect an entitlement to Carer's Allowance, but there are no indications at this stage that people who face serious health issues will be penalised by the change in benefit.

If you need any further information regarding the proposed changes to the benefits system, then please contact the Carers Service Helpline or the Disability Information Advice Line (DIAL) T: 01736 759500.

Here at Disability Cornwall, our DIAL advisers are benefit specialists and we offer free talks to community groups. Due to concern among many carers about how their benefit entitlement could be affected under the current welfare reforms, we will be happy to hold a friendly and informal talk, specific to carers, if there is enough interest. If you would like to attend then please contact us to register your interest.

T: 01736 756655

E: dial@disabilitycornwall.org.uk

# CHANGING PLACES



# Some facts and figures



There are almost six million carers in the UK and 50,000 in Cornwall alone



3 out of 5 people will become a carer at some point in their lives



Every year
2 million
people take
on new caring
responsibilities

Over a million people in the UK care for more than 50 hours a week

One in eight adults in the UK is a carer

Carers Allowance is £53.90 for a minimum of 35 hours, equivalent to £1.54 per hour

Carers News is a user led publication. If you are currently caring for someone and would like to shape and guide future editions, please contact us.

T: 01736 756655

E: carersnews@disabilitycornwall.org.uk

Photos courtesy of Carers Rights & The Princess Royal Trust for Carers