

Health and Adult Care Scrutiny Committee

# Carers Spotlight Review

12 March 2020

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This report can be downloaded from:

<http://democracy.devon.gov.uk/ieListDocuments.aspx?CId=428&MId=2855&Ver=>

## Preface

I proposed this review because it was apparent from the national biennial survey<sup>1</sup>, that many carers in Devon were struggling.

It was a thorough and comprehensive review, talking with over 100 carers, health workers and council staff.

I am confident that our team got a genuine feel for the difficulties facing many carers in Devon. Many are facing financial hardship, and say they experience regular crises. Many carers are neglecting their physical and mental health due to the demands of caring for another person 24 hours a day, seven days a week.

My fellow councillors and I have been moved by the stories that we heard, and we have felt a strong desire to do everything we can to try and help.

We very much hope that these recommendations will be agreed by the Cabinet and that the relevant agencies, as well as Government ministers, can do everything they can to improve the lives of carers, who do a truly incredible job, often in challenging circumstances.



**Councillor Claire Wright,  
Chair, Carers Spotlight Review,  
Health and Adult Care Scrutiny Committee**

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<sup>1</sup> Survey of Adult Carers in England, 2018-19 (SACE). This national survey takes place every other year and is conducted by Councils with Adult Social Services Responsibilities (CASSRs).

# 1. Recommendations

Members recognise that there is an overlap on many of the following recommendations between the County Council, NHS Devon CCG and Devon Carers. The recommendations have therefore been somewhat arbitrarily placed under a lead organisation, but it is as much for Devon's emerging Integrated Care System through the Devon Sustainability and Transformation Partnership (STP) to ensure these are effectively discharged. Devon Carers Partnership Steering Group should in the first instance be actioned to monitor the implementation of these recommendations, alongside the Scrutiny Committee.

## Local Government Association

### Recommendation 1

That Government through the Local Government Association (LGA):

- (a) works with the County Council to identify a funding stream to support carers, linked to new proposals to fund Adult Social Care, particularly in relation to the provision of replacement care. Increased resources are needed to recognise the growth in the number of carers and the longer duration of their caring responsibilities. This is essential to delivering the ambition of the Care Act 2014.
- (b) reviews the benefits and appeals system accessed by carers to ensure it is properly supportive and not leaving carers without the financial support they are entitled to.
- (c) reviews the NHS Continuing Healthcare criteria to ensure it is providing the necessary provision for carers.
- (d) recognise the skills and value of care workers and reviews their pay with a view to the provision of competitive remuneration and benefits in order to boost staffing levels.
- (e) creates a ministerial role for carers.

## County Council

### Recommendation 2

That a Carers Charter is created:

- (a) recommending a carers pathway signed up to by each agency, including primary care and consultants, outlining what carers can expect in terms of support at each stage of the process.
- (b) recommending the continued development of a clear gold standard for carers assessments to avoid variation with effective follow up procedures in place. That this model pathway is signed up by all service providers including the voluntary and third sector.

### Recommendation 3

That Devon campaigns and promotes carers income maximisation through a dedicated staff appointment.

### Recommendation 4

That relations are continued to be developed between care workers and carers using the County Council's in-house domiciliary care as a pilot to improve the way agencies work with carers.

## Recommendation 5

That the County Council reviews its needs assessment process to ensure it is taking the views of the carer into account as well as the cared for person.

## Recommendation 6

That advance communication and complementary working is developed between Devon Carers, the third and the voluntary sector, which includes longer term funding for these groups.

## Recommendation 7

That Devon Carers build into their contract a carers buddying scheme, whereby carers are matched with a trained volunteer who is also a carer (or former carer) to provide support, help and advice.

## Devon Carers

### Recommendation 8

That Devon Carers and Adult Social Care and Health Operations work to ensure a level of carers assessments consistent with nationally recognised good practice in terms of the methodology and pathways.

## Devon Sustainability and Transformation Partnership (STP)

### Recommendation 9

That the Devon Long Term Plan ensures through its Integrated Care Model that carers needs are properly recognised to ensure they get the support they need to care without putting their own health and wellbeing at risk.

## NHS Devon Clinical Commissioning Group

### Recommendation 10

That NHS Devon CCG and the County Council ensure carers' appointments and carers' elective surgery are prioritised; that medical staff know they are carers and support is put in place when they go home after surgery.

### Recommendation 11

That through the Better Care Fund (which the carers budget comes from) a resource stream is targeted at:

- a) GPs to recognise carers as a group they need to provide for;
- b) training health professionals in Primary Care Networks to recognise and support carers.

### Recommendation 12

That there is an initial health and emotional wellbeing check for all carers upon their identification.

## 2. Introduction

- 2.1 The Spotlight Review was undertaken by the following members of the Health & Adult Care Scrutiny Committee:
- Councillor Claire Wright (Chair)
  - Councillor Hilary Ackland
  - Councillor Marina Asvachin
  - Councillor Sylvia Russell
  - Councillor Jeff Trail
  - Councillor Richard Scott
  - Councillor Sara Randall Johnson
  - Councillor Andrew Saywell
  - Councillor Phil Twiss
  - Councillor Nick Way
- 2.2 Members would like to place on record their gratitude to the witnesses who contributed to the review. In submitting its recommendations, the Group has sought to ensure that its findings are supported with evidence and information to substantiate its proposals.
- 2.3 On 20 September 2018 Health & Adult Care Scrutiny resolved to set up a spotlight review on carers. The terms of reference for the review were:
- To understand the carers' offer and evaluate against the experience of carers in the County.
  - To examine the availability of replacement care across Devon.
  - To report back to the Health & Adult Care Scrutiny Committee on the findings of the Task Group.
- 2.4 Devon Carers hold both the Caring Well in Devon contract for the delivery of adult carers services, as well as the contract for Devon Young Carers. The focus of the review was adult carers of adults, and therefore largely does not reference young carers. This in no way reflects members identifying less importance to carers services for young people, but that to look in detail at this area necessitates a separate piece of work to cover it adequately.
- 2.5 Members identified it as essential to engage widely with carers as part of the review process. Visits to numerous carers groups were arranged across the County (see Appendix 1) prior to the main spotlight session, which carers also attended. In total members spoke with 121 carers, as well as receiving written representations from a number of other carers who were unable to attend any of the meetings.
- 2.6 Time and resources necessitate that this report provides a snapshot approach to highlight significant issues that carers have raised in their representations to the spotlight review. The list of witnesses to the review does not pretend to be exhaustive but it does provide insight into some of the central themes.
- 2.7 The County Council through its Joint Commissioners closely monitor the Caring Well in Devon contract, so this piece of work does not try to replicate that role but instead aims to take the voice of the carer and present the issues that matter most to them.
- 2.8 The Task Group asks the Health and Adult Care Scrutiny Committee, Cabinet and NHS Devon CCG to endorse this report and consider the recommendations detailed above.

## 3. Background / Context

### Devon Overview

- 3.1 Devon is the third largest county in England, covering 2,534 square miles. The County Council area has around 780,000 residents, with a higher proportion of older people than the national average. It is also one of the most sparsely populated counties, with few large settlements and a dispersed rural population.
- 3.2 The Joint Strategic Needs Assessment provides a summary of health and wellbeing needs across the Devon County Council area. It contains a range of information about health and the factors that influence the health of the population from a range of sources. The following population and demographic challenges in Devon were identified:
- Older than average population compared to England
  - Growing population particularly those in older age groups
  - Increasing numbers of persons typically not in the labour force aged 65 and over
  - More people moving into Devon compared to moving out of Devon, particularly those aged 30 to 69 years
  - Over 75,000 planned dwellings and 422 hectares of employment land are planned for over the next 15 to 20 years
- 3.3 The population of Devon over the last 35 years has continued to grow and is projected to increase by approximately 12% by 2039. While age groups aged 39 and under are estimated to remain relatively static, much greater increases are estimated in the older age groups by 2039, with the pension population is estimated to grow by approximately 29.5%.<sup>2</sup>
- 3.4 Estimated 14,520 people with dementia in Devon currently. Around 59% with a diagnosis (this is below the national average of 68%). The cost of social care for people living with dementia will nearly treble by 2040, a report by the Care Policy and Evaluation Centre (CPEC) has found. The research<sup>3</sup> shows that the number of people living with dementia in the UK is expected to nearly double (to 1.6 million), the cost of social care is expected to almost triple, increasing from £15.7 to £45.4 billion. The analysis found that the number of people living with more advanced dementia will rise more rapidly than the number of people living with mild and moderate dementia. As such, people will have higher associated care needs and more people will need social care for longer, increasing average social care costs. The study also estimates that families are providing £13.9 billion a year in unpaid care for people living with dementia. This is also projected to increase to £35.7 billion by 2040.
- 3.5 The Devon NHS Long Term Plan (LTP) for Health and Care - Better for You, Better for Devon sets the agenda for working together over the next 5 years. The Plan describes the population needs and case for change in Devon, along with practical actions that the system will take to deliver the commitments set out in the LTP. The Plan seeks to integrate health and care services to support the increasing demand on the system. The Plan identifies key challenges which need to be addressed to improve care for Devon's residents across the following thematic:
- Financial
  - Performance
  - Workforce and

<sup>2</sup> P.20

[https://devoncc.sharepoint.com/sites/PublicDocs/PublicHealth/Wellbeing/JSNA/Devon\\_JSNA\\_Overview\\_2018\\_FINAL.pdf](https://devoncc.sharepoint.com/sites/PublicDocs/PublicHealth/Wellbeing/JSNA/Devon_JSNA_Overview_2018_FINAL.pdf)

<sup>3</sup> <http://www.lse.ac.uk/cpec/news/number-of-people-living-with-dementia-to-more-than-double-by-2040>

- Case for change significant drivers of demand

The LTP specifically covers carers in line with national guidance: CQC Quality Markers for Carers in Primary Care Practices; Carer Passports (to improve recognition) and contingency plans to help carers understand the out of hours help available to them and to prevent carers having to face emergencies alone (while this now sits in a supporting paper rather than in the main Devon LTP, carers are mentioned frequently in the LTP.)

## What is a Carer?

- 3.6 A carer is a person of any age who provides (or intends to provide) care and/or support of any type to another person, usually a family member, sometimes a neighbour or friend (sometimes referred to as the “cared-for person”), without payment and not as part of a volunteer scheme. The “cared-for” person could not manage without this care/support.

- Carers’ work valued at £1.6bn in Devon alone
- Census 2011: 84,000 carers in Devon (includes young carers)
- Public Health estimate 2018: 86,595 adult carers alone
- More than one in 10 people in Devon are carers

- 3.7 A carer has eligible needs for support if all three of the conditions of the National Eligibility Criteria have been met:

- 1) The needs arise as a consequence of providing necessary care for an adult.
- 2) The effect of the carer’s needs is that any of the specified circumstances apply to the carer.
- 3) And as a consequence of the fact there is or is likely to be a significant impact on the carer’s wellbeing.

## Carer Health

- 3.8 Carers tend to be in poorer health compared to non-carers with higher levels of unpaid care are associated with particularly poor general health. The health of carers aged 25 to 49 is notably worse than non-carers. Levels of good health are significantly higher in non-carers in the 50 to 64 age group, and for persons aged 65 and over whilst the general health of carers and non-carers is similar, for those providing unpaid care for 50 hours or more the general health is notably worse.<sup>4</sup>

## Care Act 2014

- 3.9 The Care Act (2014) sets out the statutory requirement for local authority social services, health, police and other agencies to both develop and assess the effectiveness of their local safeguarding arrangements. Section 14 of this act links specifically to safeguarding adults. It sets out a clear legal framework for how local authorities and other parts of the health and care system should protect adults at risk of abuse or neglect. This is founded on the six key principles of:

- Empowerment – people being supported and encouraged to make their own decisions and give informed consent
- Prevention – it is better to take action before harm occurs
- Proportionality – the least intrusive response appropriate to the risk presented
- Protection – support and representation for those in greatest need

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- Partnership – local solutions through services working with their communities. Communities have a part to play in preventing, detecting and reporting neglect and abuse
- Accountability – accountability and transparency in delivering safeguarding

3.10 These six principles underpin the work of professionals and other staff who work with adults. They apply to all sectors and settings that work to safeguard adults, including care and support services, commissioning, social work, healthcare, welfare benefits, housing, wider local authority functions and the criminal justice system.

### **Carer Services in Devon**

3.11 Carer Services in Devon are provided under joint commissioning arrangements between the County Council (both Adult Care & Health, and Children's Services), and NHS Devon Clinical Commissioning Group (CCG). This arrangement is known as the Devon Carers Partnership in which Devon County Council is the lead partner. Westbank Community Health and Care were awarded the 5-year contract in April 2018 for Caring Well in Devon for adult carers of adults' service, and the Young Carers Support service for young carers.

### **The Devon Carer Offer – Key Changes**

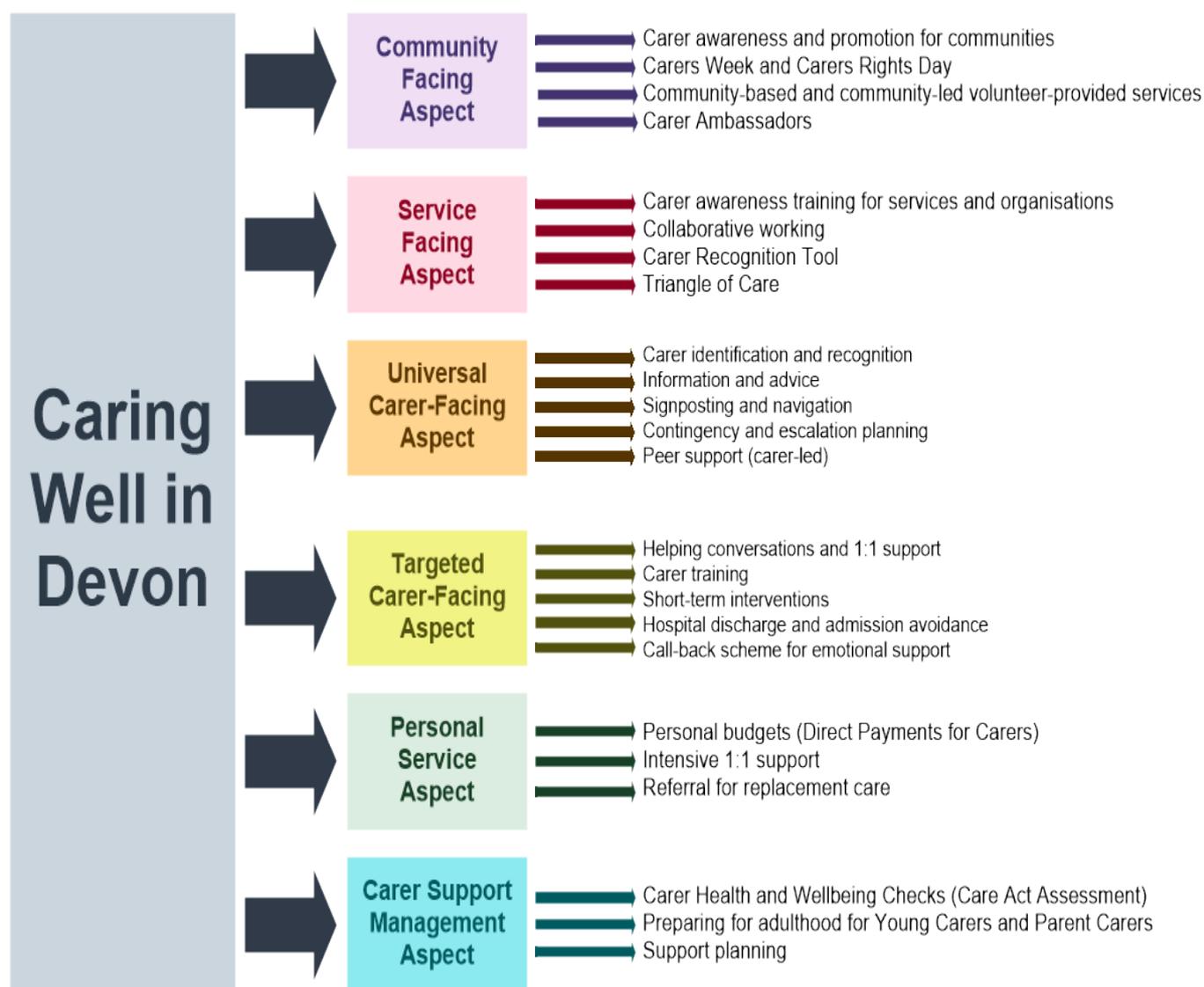
#### **3.12 The “Old Offer”**

- Take a Break - vouchers for up to 3 hours sitting service a week, contribution by the carer when redeemed
- Flexible Breaks Grants – small cash payments, once a year maximum, carer to use as wished – access on the basis of “proving the need for a break”
- “Respite Care”- on needs of cared-for person only, charged to the cared-for person.

#### **3.13 The “Post-Care Act Offer”**

- Wider range of “universal” and “targeted “services
- More 1:1 and Peer Support
- Carer Direct payments to meet Carers' “eligible needs” - more flexible than previously (replaces Flexible Breaks Grants)
- “Replacement Care” (“respite care”) – on eligible needs of carer (and according to the needs of the cared-for person) charged to the cared-for person.

## Service Model for Carers in Devon



### Survey of Adult Carers 2018-19

3.14 The most recent national Survey of Carers in England published in June 2019 used the 2018-19 outcomes following the first year of the new Devon Carers contract. The survey covers a range of questions, including those used in the Adult Social Care Outcomes Framework regarding:

- Carer reported quality of life
- Satisfaction with Support and Services
- Social Contact
- Involved and Consulted in support of cared-for person
- Access to Information and Advice

3.15 Devon's headline performance against the 5 key indicators was mixed:

- Two improved nominally: carer satisfaction and access to information and advice
- Three declined: carer reported quality of life, social contact and involved and consulted
- The national and regional picture is one of declining performance

3.16 Carer satisfaction in Devon has declined markedly over recent years in line with national trend. This may be a result of the Care Act.

## National Policy

3.17 The [Carers Action Plan 2018-20](#) sets out the cross-government programme of work to support carers over the next 2 years and covers:

- Services and systems that work for carers
- Employment and financial wellbeing
- Supporting young carers
- Recognising and supporting carers in the wider community
- Building research and evidence to improve outcomes for carers

## The NHS Long Term Plan

3.18 The NHS LTP recognises that carers:

- require better recognition and support, with many of them themselves older people living with complex health problems;
- are twice as likely to suffer from poor health compared with the rest of the population, primarily due to a lack of information and support, finance concerns, stress and social isolation.

3.19 This will be addressed through:

- Care Quality Commission (CQC) Quality Markers for Primary Care will help Practices become carer friendly;
- The national adoption of Carers Passports;
- Ensure that carers understand the out of hours options available to them, benefit from “contingency planning” conversations, and that plans are included in Summary Care Records.

3.20 Other aspects of the Plan will also assist carers, for example, access to digital Patients’ Personal Health Records. All CCG’s are required to have plans to implement these. The Devon CCG has a plan agreed across the STP.

3.21 The NHS England “Commitment to Carers”, published in 2014, set out the way NHSE wishes to improve the quality of life for carers:

- “Recognise me as a carer” (this may not always be as ‘carers’ but simply as parents, children, partners, friends and members of our local communities);
- “Information is shared with me and other professionals”;
- “Signpost information for me and help link professionals together”;
- “Care is flexible and is available when it suits me and the person for whom I care”;
- “Recognise that I may need help both in my caring role and in maintaining my own health and well-being”;
- “Respect, involve and treat me as an expert in care”; and
- “Treat me with dignity and compassion”.

These led to eight priorities:

1. Raising the profile of carers;
2. Education, training and information;
3. Service development;
4. Person-centred, well-coordinated care;
5. Primary care;
6. Commissioning support;
7. Partnership links; and
8. NHS England as an employer.

3.22 Alongside this NHSE published a Memorandum of Understanding (MOU) as part of a carers’ toolkit designed to help local NHS and social care organisations work together for

carers. In response to this MOU the Devon STP developed a “Commitment to Carers” agreed by the STP in October 2019.

This covers:

- identification and support for carers,
- making sure that carers’ support services are well integrated, that mainstream health and care services are carer friendly, treat carers with consideration and link them into support, take a whole family approach and improve access to replacement care;
- enabling carers to make informed choices about their caring role;
- staff are carer aware;
- information is shared appropriately to support carers;
- respecting carers as expert partners in care;
- supporting carers whose roles are changing or who are more vulnerable;
- our role as an employer or potential employer of carers.

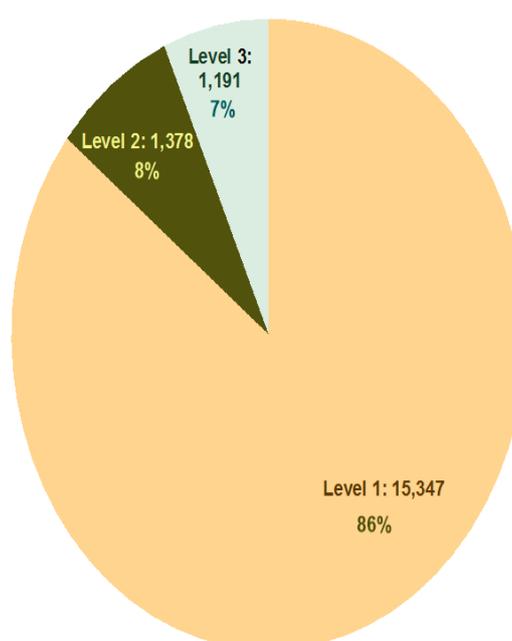
## Carers Offer in Devon

### Level 1: Universal Support for Carers

- Information, advice and guidance, signposting to resources
- Carer Newsletter
- Carer Alert Card
- Advice on access to education, training, leisure, volunteering, and employment
- Support to develop relationships and networks
- Advice on access to other services
- Apps and other online resources
- Online training
- Celebration events
- Training to care safely
- Self-organised peer support

### Level 2: Targeted Support for Carers

- Sourcing, signposting, referral to services e.g. benefits, dementia support, end-of-life planning
- Personalised advice, intervention, and 1:1 support
- Facilitated peer support
- Contingency and escalation planning
- Online and telephone carer-to-carer peer support
- Training (generic and specific)
- Hospital discharge and prevention scheme
- Casework and crisis support
- Group work
- Volunteer helpline
- Specialist service navigation



### Level 3: Personal Support for Carers

- Volunteer call back scheme
- Specialist input and training
- Carer break payments
- Short-term Personal Budgets
- Replacement Care and longer-term Personal Budgets
- One-off personal payments for carer independence

## 4. Voice of the Carer

4.1 Members spoke with 121 carers through the spotlight review process. It is their voice that is central to this report, its recommendations and findings. Detailed below is an anonymised selection of carers' very personal stories that members heard during the review<sup>5</sup>:

### 4.2 **Becky**

- Becky's husband has problems walking, he has had an angioplasty, ulcerated feet, psoriasis and three years ago a below the knee amputation and the other leg is amputated to the thigh. He also has dementia and diabetes.
- A wet room is being funded from a Disabled Facilities Grant.
- Becky has had telephone support from Devon Carers, but would prefer face to face meetings. CAB person visited. Forms are all a battle.
- Becky left him for 6 weeks this year, she could not cope any more after their son died.
- Becky's husband does not show his feelings. He cannot cope with travelling and cannot go in the car. He has several appointments a week.
- Becky tries to go out more and is doing voluntary work but is always on edge.
- Becky has help for one hour a day through PIP. Paid carer takes him downstairs, gives him a wash and makes him a coffee. He talks more to her than he does to Becky.
- Becky regrets her life and no longer loves her husband.

### 4.3 **Patrick**

- Patrick left his family in Spain 18 months ago to care for his mum with dementia in Devon.
- Six years ago when Patrick's dad passed away, his mum's care agency said she needed 24 hours a day care. She has bowel cancer and has a colostomy bag. She picks off the bag which creates a mess. Carers come in for 45 minutes in the morning and 30 minutes in the evening. There was a November 2018 prognosis, but she has outlived it.
- Patrick's mum had a CHC assessment and is funded by the NHS.
- Patrick misses his family and feels as though he is wasting his life. Patrick feels trapped but does not want to leave mum. Patrick gets four weeks paid respite a year.
- Patrick wants to find a decent care home in Devon and has so far visited 20.

### 4.4 **Claudia**

- Claudia started caring for her father in 2008. Each time Claudia's father went into hospital it got worse. Sent home without a carers assessment. Moved into a bigger house so that he could move in with her, but then funding stopped as a result.
- Getting into a care home was incredibly difficult. Respite or permanent care. Advanced level of dementia seemed to cause problems.
- When back at home let down repeatedly by personal care, with workers changing/not turning up.
- Went back to care home but could not afford it. He should have stayed in his own accommodation to continue to receive 16 hours per week social services funding
- There was a lack of support and advice to help to resolve the problem.
- Case was borderline and told to return if needs deteriorate. Complex Discharge Team from the RDE refused a second CHC assessment in 2018. Threatened to go to Australia and leave her father before support was provided. Checklist proved positive so a full assessment was organised
- Framework states that it does not matter where care is being provided but was told with CHC funding only eligible for nursing care, not a care home.
- Devon Advocacy were excellent.
- Constantly receiving conflicting information to the National Framework.

<sup>5</sup> It should be recognised that some of the experiences carers have outlined may not be recent. However, all of the cases were followed up by officers after the disclosure of this information.

- Issues with discharge. Wanted to bring her father home, but he was sent to a care home. Emotional support to deal with this was nonexistent.
- Claudia feels that if she had used a solicitor, she would have got the funding. There seems to be a lack of support in the system.
- Her father is now back at home with a live-in carer – it is working. Her father is now content. Would not have him in a vegetative state in a care home.
- Claudia has felt lonely and isolated throughout this process.
- Hours spent researching on the internet to get the information needed to move forward, with regard to care needed and definitive information regarding funding.
- Claudia wants to use her experience to help and enable others. Wants to do work with carers on building resilience.

#### 4.8 **Gaynor**

- Gaynor had to give up her job to look after her mum who has been left physically disabled and wheelchair bound.
- Gaynor's mum cannot do anything by herself. Did have care package put in place, but the agency staff coming in were not always nice to her mum, nor did they understand her needs. Went on to direct payments which helped.
- In Exmouth, she did have some very good carers but with a high turnover of staff it has been a real problem. A couple of agencies cancelled their contract saying they did not have carer worker.
- Life is a constant battle in terms of organising her mum's care. Gaynor has lost her direct payment now, with Adult Social Care paying for her care. Gaynor stated that her payments for an hour of cleaning a week, as well as a Pilates and her Crealy pass all stopped at once.
- In November 2018 a direct payment did not come through for 4 weeks residential care respite. Gaynor stated that Care Direct said that system has changed and supposed to ring every time at risk of carers breakdown. Gaynor last had a break in September 2018.
- Gaynor receives £64 carers allowance a week. May need to review her benefits but concerned about move to universal credit and do not feel able to cope with the stress. Gaynor has had some financial issues. A charity wrote off £700 debt to South West Water.
- One of the hardest things is navigating the system. It has had a profound impact on her mental health as a result of the stress. It has made her feel very anxious, and inadequate. She has lost her career and confidence.
- Gaynor's mum goes to 3 groups and loves going to them, but there is nothing in Exmouth so she has to drive her mum to Exeter. Transport would be helpful.
- Carers assessment this year has been wonderful. Devon Carers provide good support, and her ASC worker currently is very good.

#### 4.9 **Sharon**

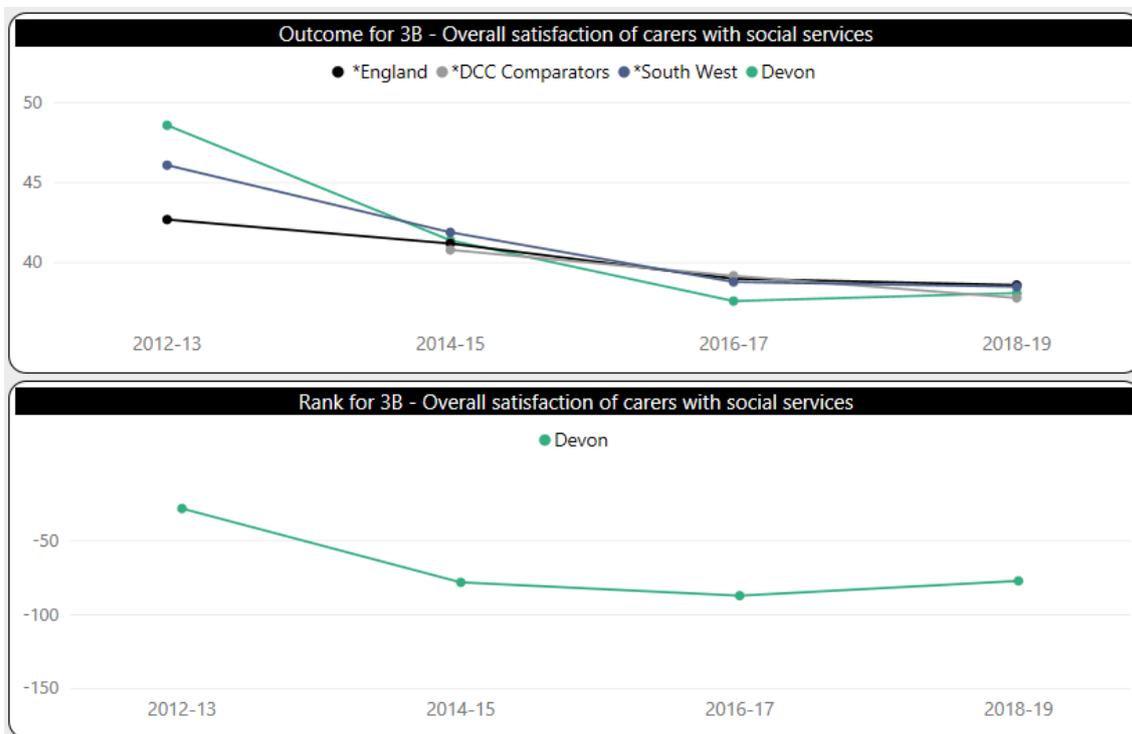
- Sharon's husband has Motor Neurone Disease.
- Sharon had a fall last year, and her husband had to go into a nursing home for 3 months.
- He is now back at home - he needs double-handed care, but they cannot afford 2 carer workers, so Sharon is acting as the second care worker.
- Physical as well as emotional strain.
- Sharon's husband is effectively locked in. He can write but difficult to keep up with a conversation, so he tends to shut down. It is not easy to have either friends or family. He does not go out at all.
- The care workers are always changing so they do not know Sharon's husband, and in turn he does not like the carers, or want them coming in.
- Sharon does not feel she has had any support as a carer. She last had a carers assessment in 2014.
- Sharon's husband would not accept having anyone in to talk to him. Tried in the past, and it lasted 3 sessions. She has a window between 11.30am – 3pm every day, her husband cannot move so will sit and watch TV.
- Sharon did not get CHC despite not being able to do anything. The financial side is a big worry.

## 5. Key Issues

- 5.1 Key issues arising from the witness interviews are presented here. The interview methodology was open ended, and conversations ranged over many topics. Hence as the issues were covered from different perspectives and reflect the interests of more than one interviewee no attributions are given.

### Carer Satisfaction

- 5.2 The spotlight review heard from many carers who did not feel satisfied by the support they had received within the health and social care system. Carers who felt that their needs had not been adequately met by the County Council and NHS, as this review will outline. There is still a different provision of services across the localities for carers depending where in the County someone lives. Work needs to be undertaken in terms of identifying where those gaps in services are and what services and interventions can be brought in to make a difference to carers. However, there was consensus during the review process that through the new Devon Carers contract improvements had been made to the carers offer and experience. Both carers and staff reported that co-production and co-design of the Caring Well in Devon contract for the delivery of adult carers services had been extremely positive. Universal praise was also voiced for the County Council's Joint Carers Lead, who has worked tirelessly to ensure both the adequacy and prominence of carers services through her role managing the Devon Carers contract.
- 5.3 The performance metric *on overall satisfaction of carers with adult social care services* places Devon's performance in line with the national, regional and comparator averages making it midranking. This national, regional and local decline has coincided with the implementation of the Care Act (2014) nationally<sup>6</sup>.



<sup>6</sup> P.77

<https://democracy.devon.gov.uk/documents/s29491/Annual%20Report%202019%20for%20SCRUTINY%20v2.pdf>

## Identification of Carers

- 5.4 There is a need to ensure that those who find themselves in a caring position are identified as carers and the individuals given adequate information regarding caring. Many carers are hidden and some may not want to be called a carer. They also may well not encounter social, health or voluntary services that could help. It is therefore essential that professionals are proactive in recognising when a person may be caring for someone. They can then signpost these individuals to local information and support. The role of Primary Care as the one to which all carers have access is recognised as paramount in identifying carers more quickly and before their health and wellbeing deteriorates. GP surgeries need to be better coordinated to identify carers, some of whom may not realise that they themselves are carers.
- 5.5 The County Council did not get the large increase in carers coming forward for help from Adult Social Care that had been planned for post the 2014 Care Act. Increasing the number of identified carers is challenging because of the rate of carer “churn” – the rate of carers leaving and joining the population of carers is significant. However, at the end of Q1 in 2018/19 (the contract started in May 2018) there were 17541 carers identified at Devon Carers, 20.2% of the estimated total adult carer population in Devon at that time, to the end of Q3 of the current year there are 19,892 22.7% of our current estimated carer population. This is ahead of the base requirement and ahead of the Devon Carers bid numbers. The County Council have a shared ambition with Devon Carers to go further than this.
- 5.6 There is a significant discrepancy between the number of carers on the County Council’s CareFirst system, and the number registered with Devon Carers. The gap currently is about 10,000 people on CareFirst not known to Devon Carers. Emphasis should be given to referring carers unless they say otherwise, rather than just provide information on Devon Carers and ask them to make contact. It must however be noted that it is not an automatic assumption that all carers want to be in contact with Devon Carers, nor the outcome in terms of support following an assessment.
- 5.7 Carers need to be aware of the support services available to them to ensure their own wellbeing is looked after while providing care. As part of carer identification, it is important conversations are taking place with people about the label ‘carer’. Are they the best person to be the carer? Do they want to do it? It is problematic where someone feels captive in that role. Also, the system needs to acknowledge and recognise the husband/wife dynamic where they have been this couple and then it changes to one of them being a carer - it is quite a shift and incredibly nuanced.

***“I am treated for stress all the time; I am on medication, but I don’t want medication I want respite”***

**Carer**

## Primary Care

- 5.8 The importance of GPs, as well as receptions at GP practices, in understanding and identifying the carers role cannot be overstated. GPs need to put carers in touch with Devon Carers before they reach a point of crisis. Members received feedback that in some instances after the initial meeting with a GP about their cared for person, carers often felt a lack of empathy and support following a dementia diagnosis. Numerous concerns were raised about delays in access to primary care, whether these could lengthen as demand at GP practices increases and the potential impact on carer identification and support, which already felt limited.
- 5.9 There were examples cited of GPs looking at a carers situation holistically rather than just dealing with individual medical problems. In some practices GPs provide annual health checks on carers wellbeing. Officers advised that they have seen a positive trend of GPs making more referrals and being increasingly aware of carers, although some staff need to think more about the carer rather than just the cared for. Ideally all carers should be

identified and referred on to Devon Carers but GP's do not always have the expertise nor the capacity to do this themselves.

- 5.10 It was apparent to members that in terms of primary care there is a gap between what is commissioned for and the level of support carers expect. The role of primary care currently is mainly one of recognition and signposting onwards to Devon Carers services. There are not any responsibilities to carers which GP's are specifically contracted to provide and this is most probably why there is an inconsistency of offer. It is hoped that various aspects of the new specifications which the new primary care contract is determining will encourage more targeted support to carers. Those GPs who are engaged will have posters, leaflets, information on their websites. Primary Care Networks should help with the Sustainability and Transformation Partnership (STP) commitment to identifying carers moving forward to an Integrated Care System (ICS).
- 5.11 It is hoped that with the new primary care contract from 1 April 2020 - anticipatory care – will ensure GPs are more focussed on integrated care and carers. Carers services and needs are also being written into software so that professionals ensure carers are considered. Carer Awareness Training is one of the 'Big 3 Improvements', along with replacement care and breaks, that have been identified in terms of carers services.

***"I have been brought to the absolute brink by this. There's been no one to signpost me where to go to get accurate advice especially on funding."***

***(Carer)***

## **Carers Assessments**

- 5.12 The Care Act 2014 introduced new rights for carers to have their needs assessed if there is an appearance of need, and placed duties on local authorities to provide for those needs if they eligible. There is a statutory requirement on councils to provide carers' assessments and, if the carer has eligible needs, replacement care is required to meet those needs, and if the cared-for person consents and is willing to pay. However, the quality of these assessments and respite care across the country appear to be mixed. Nationally 1.3 million people are entitled to a carer assessment but only approximately 300,000 have received it.
- 5.13 Dissatisfaction with carers assessments in Devon was an issue highlighted to members. The process for carers assessment was repeatedly described by carers as nightmarish. While it was apparent during the review process that some individuals were confusing a carers assessment with a financial assessment, it did appear that there may be some discrepancies with carers assessments in terms of the level of support provided by Devon Carers and Adult Care and Health Operations during and after the assessment.
- 5.14 In some areas it was reported that carer assessments have been treated as a box ticking exercise to the extent that carers may not even realise they have had such an assessment. Sometimes an assessment might be good, but the follow up is poor. Data collection is important, in terms of when carers are assessed and what their caring responsibilities are and monitoring patterns.
- 5.15 Concerns were raised by carers that there have been instances where they have not been involved in the assessment for the cared for person, despite guidance being clear that they should have been.
- 5.16 The spotlight review heard that the Alzheimer's Society is currently undertaking research that specifically looks at carers' assessments and carers' respite, within the context of dementia carers. As part of this project, researchers are looking at good practice and what the barriers are to deliver that good practice. The study cuts across a range of areas, including the

psychological health of the person living with dementia; the impact of different types of dementia on living well; and comorbidities. The study has so far explored the experiences of more than 1500 people with dementia, and more than 1200 friends and family of people with dementia. Based on the findings, Alzheimer's Society are aiming to develop clear, targeted recommendations for local authorities for better outcomes for those carers and the people with dementia they care for.

***“There’s no respite and when things aren’t working it’s a bloody nightmare.”***

***(Carer)***

### **Information, Advice and Guidance**

- 5.17 Information is a core universal service and key in early intervention and reducing dependency. Improved and/or more information benefits carers and the people they support by providing greater choice and control over their lives. Carers reported that despite recognising improvements Devon Carers have made to help support people through the system, up to date and accurate information could still be difficult to find. Given the daily pressure carers must contend with, they do not have the time to hunt for information.
- 5.18 The County Council website [carers pages](#) among other resources has a digital offer called the *Upfront Guide to Caring* which generates a personalised information “prescription” for individual carers at all stages of the journey. Efforts need to be made to publicise better on the website the information available to carers so that interventions are made earlier before crisis point. Devon Carers webpages need to have search engine prominence on Google.
- 5.19 Recognising that carers are often at the end of their tether, members welcomed work Devon Carers lead on resilience and helping carers to acknowledge the skills they have, both in terms of caring and looking after themselves. It helps if work is undertaken with carers on conditions such as dementia as to why people behave in such a way and offer some solutions. Devon Carers try to create answers to the questions carers ask, curating the best practice and most accessible advice available, sharing top tips in terms of being a carer. Signposting is an important role, also for staff across the health and care system who also may not always know where to go. People are often not identified at the right point of the journey. Devon Carers are now doing more of a road map, highlighting steps in the caring journey, coupled with the website and helpline. The Dementia Carers Pathway handbook, which was created by two carers has recently been revised and re-printed by Devon Carers. Work needs to continue to be progressed in terms of how local areas can use community champions to more effectively link people to support and services.

***“It is easy to slip into a caring role and assume that you are simply being a wife or husband, for example, and not realise that you are a carer.”***

***(Carer)***

## Single Point of Contact

- 5.20 Carers want a single point of contact between Health and Adult Social Care, and a single point of access. In the initial stages of caring it was reported to be confusing to have multiple points of contact to seek out. Carers want someone at the other end of the phone who is empathetic and can provide emotional support. They want someone to listen to their concerns and help them to think through their problem and, if needs be, signpost to further support. Carers complained about being passed from one agency to another repeatedly having to tell their story. There needs to be a more joined up approach as Devon moves to an Integrated Care System, where there is a three-way relationship with professionals which fully includes the carer as well as the cared for person as a package rather than individuals. Carers reported experiences of health professionals failing to acknowledge the carer in terms of the cared for person's appointments/treatment. Carers expressed concern that the cared for person may give a more positive impression of how things are. Assessments need to listen to both the carer and cared for to ensure help can be implemented accordingly.

***"I feel stressed and am up to here (points to head) with it. I need respite but I don't get a break."***

***(Carer)***

## Financial Challenges

- 5.21 Most carers members spoke with as part of the review process advised that they were either currently living in financially challenged circumstances or were worried about being able to afford a care home as their cared for person's condition deteriorated. Significant financial challenges were reported for younger carers of people who might be in their 40s/50s supporting a partner with chemotherapy if they need to take time off or cease to work. It can end up with people feeling that they may get more support where the carer does less.
- 5.22 There are different Personal Budgets that carers can qualify for in Devon: short term payments, long term payments, carers independence payment etc. Anyone eligible under the Care Act can get a personal budget, which is not means tested like replacement care. However, getting access to benefits including Personal Independent Payment (PIP) and carers allowance were fraught with difficulty and cause considerable stress and frustration, with carers giving examples of the problems, which included losing paperwork, long delays and time-consuming procedures; some carers were forced to take the tribunal route, which added further stress. People need an advocate to support completing attendance/carers allowance forms which were described as impossibly complex.
- 5.23 A disconnect was reported between access to statutory benefits and local benefits. Trying to access NHS Continuing Healthcare Funding<sup>7</sup> felt to many carers a confrontational process – people were left frustrated by not being able to get what they are entitled. Carers also worry that by challenging the assessment they may end up with less. Devon Carers advised members that they were not contracted to support the technical aspect of filling in application forms but could look at how more support could be offered in terms of NHS Continuing Healthcare.

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<sup>7</sup> NHS Continuing Healthcare is a package of ongoing care that is arranged and funded solely by the NHS specifically for the relatively small number of individuals (with high levels of need) who are found to have a primary health need. Such care is provided to an individual aged 18 or over to meet health and associated social care needs that have arisen as a result of disability, accident or illness. NHS Continuing Healthcare is free, unlike support provided by local authorities, which may involve the individual making a financial contribution depending on income and savings. It is the responsibility of the CCG to decide the appropriate package of support for someone who is eligible for NHS Continuing Healthcare.

## NHS CHC Process



- 5.24 Those carers receiving benefits/financial support for themselves and/or their cared for person overall felt more supported by the system in contrast to the self-funders who, in the main, felt they were left to their own devices. There does appear to be some lack of joined up action on the ground between health and social care in this the developing Integrated Care System. Carers reported going into hospital for treatment, and not being offered any supported care for their cared for person.
- 5.25 Carers highlighted concern relating to the impact of the statutory financial assessment and reported the loss of benefits which had left them financially challenged.
- 5.26 Self-funders found that there seemed to be nothing in-between the voluntary service and the expensive personal care service. One carer gave an example of an organisation in Norfolk called Night Owls, who she could call when she needed her husband to be turned. This meant she did not have to pay for a night sitter all night which as a self-funder made a huge difference to their budget. Other carers advocated a befriending or buddying scheme where the person could be supported.

***"I feel guilty for going out and being able to go while my husband cannot. He has lost his life, but I've also mostly lost mine."***

***(Carer)***

### Replacement Care

- 5.27 *Replacement care, also commonly known as respite care, is any care arrangement designed to give rest or relief to unpaid carers. It aims to support carers to have a break from their caring responsibilities. There are many different types of replacement care including:*
- *day centres*
  - *care at home*
  - *a short stay in a care home*
  - *holidays or short breaks*
  - *carers' emergency replacement care schemes<sup>8</sup>*

<sup>8</sup> <https://www.alzheimers.org.uk/get-support/help-dementia-care/replacement-care-respite-care-england>

- 5.28 From the Devon Adult Carers Annual Survey 2018 results, the highest thematic raised by carers related to the lack of breaks and respite available to them. Mirroring the findings from the survey, members received a plethora of representations from carers during the review highlighting their difficulties accessing respite. In fact, the number one response from carers when asked if there was one thing that would help them manage more than anything else, they said respite provision.
- 5.29 *Take a Break* was a county-wide scheme which ran until 2015 that had given carers a single route by which to arrange daytime or evening breaks from their caring responsibilities. *Take a Break* offered carers what they described as ‘a sense that there was someone out there caring’ and helped them ‘feel less alone’. The *Take a Break* voucher system was clear for carers to understand and access, while now it appears to some that access to respite is much more judgement based and this is a very different culture. Officers advised with the Care Act the law changed and resulted in this cultural shift, where the County Council subsequently could not financially sustain *Take a Break*. *Take a Break* was not personalised or responsive enough, not lawful as carers were contributing to the costs and not financed to cover the potential costs by a factor of several millions. *Take a Break* was replaced with a carers personal budget, but these have not yet been taken up as expected.
- 5.30 There are a lot of issues around taking up replacement care. The Caring Well in Devon (CWID) contract does not include alternative respite provision. Carers spoke of a lack of day care provision in their locality and respite being offered significant distances away. This has been compounded by difficulties in developing the booking system for replacement care and breaks, and work was underway to resolve this issue. Officers reported continuing to explore different options to increase the type of replacement care available to carers, such as arrangements with a host family as an alternative to a care home.
- 5.31 There are also issues around some cared for people who do not accept that the carer needs a break. Many carers spoke of putting aside their own health in favour of the cared for person. Some carers spoke of their husbands relying on them totally, who would not accept outside care coming into the house. They needed support in talking around their spouses to see that they, the wives, needed time to themselves and respite.

***“Help doesn’t come to you; you have to be bold. Help should be there for everyone.”***

***(Carer)***

## **Crisis Support**

- 5.32 Carers reported that crisis moments happened frequently because life was so hard, lonely and gruelling. Some carers experience high anxiety levels to the detriment of their mental health. In times of crisis, a lack of support to carers was highlighted as a significant issue. For some carers this was exacerbated by family not living in the area and friends not necessarily having the time to fulfil a caring role with their own problems to deal with. Also, it was reported that friends seemed to disappear as conditions deteriorated and carers were left further isolated.
- 5.33 In crisis some carers used their local memory cafe or contact the local carer ambassador who can initiate necessary statutory support through Care Direct Plus or Devon Carers on their behalf with their permission. It was felt at times that staff across the social care and health system can get fixated on process, rather than how best to respond to the individual and how best to meet their needs. However, the ongoing problems remain about a lack of care workers available to book for respite and for some people where there are enough carers, the cost of the service.

- 5.34 Several carers referenced the need for 24-hour support and identified the lack of out-of-hours support as a serious deficiency in the service offer. Officers advised that the Devon Carers Helpline, part of the CWiD contract, is available currently from 8 am to 6 pm Monday to Friday and Saturday 9 am to 1 pm. Under the previous contract the Helpline was mainly an access to the carers' service, now it is increasingly becoming a wider source of information and support for carers, as distinct from and additional to an information resource about the support available from Devon Carers. The Helpline is complemented by a web resource which has been significantly improved under the CWiD specification and provides links to services external to Devon Carers. This includes, at the head of the landing page, a button for "I need help now", which provides links to emergency numbers. The Helpline is currently being incorporated into a wider approach of "contact centre" which better recognises the different ways carers increasingly want to interact with the service including a range of out of hours support options.

***"I was originally caring for my mother 24/7. Now caring for my sister. In six years, I have had no break and became very ill. I came out of hospital after an operation in January and was told I would get support but I received no help at all. I was paying £70 a day for taxis so my sister could visit me in hospital. When you don't have money you're not entitled to support."***

**(Carer)**

## Hospitals

- 5.35 Carers reported a lack of consistency regarding out of hospital care plans. Carers also felt that at times consultants were not sympathetic to their needs. They said they were just left to get on with it: no forward referral to any support service or to a person who could signpost to support. Officers advised that it should not be the case that there is a crisis when someone is going in for a pre-planned operation. Care needs should be identified a few weeks beforehand and the system can then work together to ensure appropriate support there.
- 5.36 Devon Carers Hospital Discharge Service is there to offer the carer additional support in coping with an unexpected admission into hospital. This service looks to address concerns arising from the possible increase in caring responsibilities following the discharge to home of the cared for person.

***"I'm not coping' – if you say that to Adult Social Care no one comes to help. I need someone to lean on as a lone carer, so I can get back up and on with the job of caring."***

**(Carer)**

## Residential Care

- 5.37 Many carers reported difficulties in finding a suitable care home. Carers referenced a perceived move against funding residential care post-Winterbourne View<sup>9</sup>. Carers raised concern about the closure of residential homes across the County, and a lack of infrastructure being put in place, including nursing and residential care, to meet the needs of the population given the level of housing being developed and the increasing number of retired people living in Devon. With a higher number than average of older people, impact on access to services is a concern given difficulties already in terms of recruitment and staffing for care homes.
- 5.38 Officers advised that the County Council place far fewer people in care homes than they used to with a range of ways in which peoples care needs are now met. Those people that are going into care homes need a different kind of building and different type of care, which is why some homes have closed. There are currently about 40 people at any time with complex needs requiring a care home bed.

***“I feel trapped. My husband is reliant on me. He has significant problems, he has had a heart op and has cancer. He assumes he can come everywhere with me. I can’t get out to exercise and I have put on weight. I have just one hour a week break to do the shopping! My daughter pops in for a chat but she works full time. Generally, people don’t understand what it’s like to be a carer. “***

**(Carer)**

## **Personal Care**

- 5.39 It is estimated 25,000 people in Devon are employed in social care, 85% in the independent and voluntary sector, 10% self-employed and 5% by the local authority with around 1,500 vacancies at any time. They work for a range of commercial and voluntary sector organisations including almost 500 providers regulated by the Care Quality Commission.<sup>10</sup> There are significant recruitment and retention issues across all sectors of the health and care system in Devon, as there is nationally. There is a lack of care workers across the County (in the region of 100 care workers). Subsequently there are issues where agencies do not have the staff and cannot send a care worker out. Care workers changing frequently is problematic for someone with dementia in particular. There are also more people at home with complex health and care needs having to be supported. As a result, carers are concerned about administering drugs and are not supported or prepared for the responsibilities that can befall them.
- 5.40 Commissioning arrangements should reflect the need for care workers to work together with carers.

***“I feel trapped. I can’t even go bowling, as I’m caring 24/7 with no break. I am on edge all the time. “***

**(Carer)**

## **Carers Engagement**

<sup>9</sup> Staff mistreatment and abuse of patients at the private Winterbourne View Hospital, which first came to light in May 2011 on the BBC’s Panorama documentary. <https://www.nhs.uk/news/medical-practice/winterbourne-view-failures-lead-to-care-system-review/>

<sup>10</sup>P.4

<https://democracy.devon.gov.uk/documents/s21595/Promoting%20Independence%20in%20Devon.pdf>

- 5.41 Members received numerous representations to suggest that carers are often not connecting with their local carers group. There appears to be significant scope to reach out to more carers who may need peer support. The Devon Carers contract emphasises collaboration with the service aligned to the integrated care partnerships and Devon Partnership Trust, which should help to promote and develop the network of carer champions.
- 5.42 Care Ambassadors were identified as a positive force undertaking a huge amount of work in their role through the CWiD contract. Carer Ambassadors are an invaluable resource bringing issues relating to carers forward. The Carer Ambassador's role is also crucial in helping carers to know what is available in the community.

***“My husband has diabetes, and bladder/bowel problems. He is so frail, can't get out of bed on his own, and needs help using toilet. I get up in the night to change bedsheets twice a week at least. “***

**(Carer)**

## **Dementia**

- 5.43 Given there are few medical treatments for dementia, support for the conditions most often comes under social care rather than the NHS, even though it is a medical condition. As such, support offered is means-tested and people can find it much more challenging to get any necessary adaptations paid for. Alzheimer's Society is working to try to get all types of dementia under the NHS and are campaigning for the extra costs to people associated with the condition being free at the point of use, as they are for most other medical conditions.
- 5.44 Alzheimer's Society's direct delivery in Devon is commissioned by the County Council and NHS Devon CCG. Alzheimer's Society effect change through national and local campaigning and advocacy; direct services and research to cures and drugs. The main referral source is the Memory Service, but Alzheimer's Society receive referrals from all statutory and voluntary services as well as self-referrals. They currently receive around 560 new referrals per quarter (both people with dementia and carers).

***“My biggest worry is if I die before my partner. I worry sick about the future and who will look after my husband should something happen.“***

**(Carer)**

## **Dependency**

- 5.45 Devon Carers seek to support people to be less dependent recognising that lifestyle will need to change to accommodate the care needs of the person. Over dependency can happen with carer concern over safety issues. People may feel it quicker to do things themselves especially if they do not understand why the person's behaviour is changing and this need for the person to retain as much independence, value and self-esteem as possible. Devon Carers advice to carer groups is to 'use it or lose it' in terms of doing things. It is important to convey the message for people starting on their carer journey – to keep doing what they are doing in terms of daily life, socialising, activities and doing things for themselves. It is also vital to introduce other people into care partnership as early as possible. Devon Carers tries to support people in spending time together at home and out in

the community if they can such as through gardening, museum groups etc. An element of co-dependency is often inevitable as one of the couple steps in to caring role.

***“My husband was diagnosed with mild dementia five years ago. He won’t let me out of his sight. He was only okay about my coming here today (the spotlight review) as he thinks it is official business. He doesn’t remember what he is doing and is angry and frustrated. I get very upset about not being able to get out of the house, even for a little walk.”***

***(Carer)***

## 6. Conclusion

- 6.1 The incredible (and often tough) role that carers play in the County needs to be recognised and celebrated. First and foremost, this report must pay testament to those individuals.
- 6.2 From carers feedback there emerged a consistent set of themes. Carers are often lonely and isolated, some may be subsumed wholly in their caring duties: exhausted, stressed, and angry with a system that all too frequently seems to fail them. Carers reported their daily struggles and a sense that they not been listened to. A lack of humanity within the system was cited.
- 6.3 Devon County Council's commissioned carer's support service, Devon Carers, recognise the need to improve how they reach people so that carers are aware of their role and the support they can provide before crisis point occurs. The carers contract has a community facing aspect about developing a wider response to carers. Key to this work is the identification of carers across the system. Carers often may not self-identify or associate with the term 'carer', so this is not without significant challenges.
- 6.4 Carers assessments need to continue to take a strength-based approach focussing on what carers are doing well. It is important to recognise that is not necessarily the practical help carers always want but the opportunity to talk to someone who understands; who can offer empathy and positive reinforcement.
- 6.5 There is much more that can be done to support carers. And there is a leading role for Government in this too. The task of providing support to Devon's carers, spans NHS secondary care, primary care, the voluntary sector and the County Council.
- 6.6 Services need to be responsive, fast and effective. Carers should never feel isolated, alone, have nowhere to turn, be in poor physical and mental health, or be in frequent in crisis. Carers should feel supported, healthy, and be able to take regular breaks if they wish.
- 6.7 It is hoped that the recommendations at the front of this report will be taken on board by the relevant authorities, including ministers in Central Government, and acted upon swiftly.
- 6.8 It is vital that the Government, the County Council, the NHS and other partners do everything they can to support carers, as they all share the responsibility. If Devon looks after its carers, then they can effectively care for their loved ones.

**APPENDIX 1****Spotlight Review Activities**

- A1.1 On **4 June 2019** Councillors Wright (Chair), Asvachin, Scott, Trail, and Whitton (Health & Wellbeing Board) met with 25 Carer Ambassadors from across the County at the Devon Carer Ambassadors Network meeting at Westbank, Exminster.
- A1.2 On **15 June 2019** Councillors Wright (Chair) and Scott visited Tavistock Carers and met with approximately 25 carers.
- A1.3 On **27 June 2019** Councillors Wright (Chair) and Peart attended a session with Teignmouth Carers and met 5 carers.
- A1.4 On **28 June 2019** Councillors Wright (Chair) and Scott met 30 carers at Bideford Carers.
- A1.5 On **3 July 2019** Councillors Wright (Chair), Scott and Twiss attended Dawlish Carers and met 1 carer.
- A1.6 On **12 July 2019** Councillors Wright (Chair), Trail and Twiss members met with 6 carers at Seaton Carers.
- A1.7 On **15 July 2019** the main spotlight review took place at County Hall.
- A1.8 On **19 July 2019** Councillors Ackland (Chair), Randall Johnson, Scott and Trail met with 14 carers in the Dewdney Unit at the Exmouth Community hospital site and in attendance was the Devon Carers Co-ordinator for Carer Ambassadors and a Carer Ambassador.
- A1.9 On **14 August 2019** Councillors Randall Johnson (Chair), Scott and Twiss visited Honiton Carers Support Group and received evidence from 20 carers who attended the session.
- A1.10 On **10 October 2019** members met the Senior Commissioning Manager (Market Management, Personal Care and Carers) and the Joint Carers Lead to consider the Survey of Adult Carers 2018-19. Members also discussed their draft findings.
- A1.11 On **7 November 2019** members met with Services Manager (Devon and Torbay), Alzheimer's Society and the Regional Public Affairs and Campaigns Manager (London and the South), Alzheimer's Society; the Clinical Lead Eastern Locality, NHS Devon CCG / Chair East Members Forum / GP Partner, Coleridge Medical Centre and the Lead Practitioner for Dementia and Older People's Mental Health, Devon Carers.
- A1.12 On **30 January 2020** members met to discuss their draft findings and recommendations.

## APPENDIX 2

## Contributors / Representations to the Review

- **121 carers spoke directly to members through the review**
- **8 additional carers written representations**

Further witnesses to the review in the order that they appeared at the main spotlight review and any subsequent follow up sessions:

<b>Witness</b>	<b>Position</b>	<b>Organisation</b>
Sue Younger-Ross	Joint Carers Lead	Devon County Council/ NHS Devon CCG
Ian Hobbs	Senior Commissioning Manager (Market Management, Personal Care and Carers)	Devon County Council
Paul Giblin	Involvement Manager	Devon County Council
Jayne Bramley	Community Cluster Team Leader – Sidmouth	Hospiscare
Helen Toker-Lester	Integrated Personalised Care Delivery Lead Devon STP	NHS Devon CCG
Billy Hartstein	Manager	Devon Carers
Kerrie Dale	Involvement and Engagement Manager	Devon Partnership Trust
Tim Golby	Joint Associate Director of Commissioning, Devon County Council	Devon County Council/NHS Devon CCG
Rosemary Whitehurst	Trustee	Healthwatch Devon
Katie Buckley	Social Work Services Manager	Devon Carers
Rebecca Hudson	Senior Commissioning Manager, Disabilities and Mental Health	Devon County Council
Sophia Holmes	Senior Commissioning Officer for People with Disabilities	Devon County Council
Heather Mills	Commissioning Development Officer	Devon County Council
Matthew Byrne	Chief Executive	Westbank Community Health and Care
Chris Cruise	Deputy Assistant Director, Community Health and Social Care Services	Devon County Council / NHS Devon CCG
Isobel Ross	Team Manager – Assessment & Support Planning, Care Direct Plus	Devon County Council
Solveig Sansom	Joint Associate Director of Commissioning – Southern	Devon County Council / NHS Devon CCG
Sonja Manton	Director of Commissioning	NHS Devon CCG
Councillor Carol Whitton		Health & Wellbeing Board
Sadie Clarke	Awareness and Digital Manager	Devon Carers
Claire Tatton	Services Manager (Devon and Torbay)	Alzheimer's Society
Tom Redfearn	Regional Public Affairs and Campaigns Manager (London and the South)	Alzheimer's Society

## APPENDIX 3

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- Support for Carers / Young Carers Task Group Update Report, People's Scrutiny Committee, DCC (2013)
- Carers Event at Westbank, Health & Adult Care Scrutiny, DCC (2018)
- The Lives We Want to Lead, LGA Green Paper for Adult Social Care and Wellbeing, LGA (2018)
- Promoting Independence – 5 Year Plan for Adult Social Care in Devon
- Devon Joint Strategic Needs Assessment 2018, DCC (2018)
- Our Carers Charter, Somerset Partnership NHS Foundation Trust

### Assorted News Articles

- <https://www.devonlive.com/news/devon-news/how-many-care-home-beds-2936449>
- <https://www.mirror.co.uk/news/uk-news/best-worst-areas-uk-social-14626774>
- <https://healthwatchdevon.co.uk/replacement-care-survey-report/>

Members wished to highlight the offer by Devon and Somerset Fire & Rescue of a free home safety visit for the vulnerable including anyone over 65:

<http://www.dsfire.gov.uk/YourSafety/SafetyInTheHome/Index.cfm?siteCategoryId=4&T11D=35>