Joint Carers Strategy for Northamptonshire
2015-2018
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Introduction

This Adult Carers Strategy sets out a new model of how Carers in Northamptonshire will be supported by the County Council and Nene and Corby Clinical Commissioning Groups (CCGs) and our partners from April 2016.

This strategy has been developed with Carers, voluntary sector and statutory partners through a Carers Commissioning Group and Carers Partnership Board and informed by the Joint Strategic Needs Assessment 2015 which outlines the health and social care priorities for Northamptonshire. A separate strategy will be developed for Young Carers under the age of 18 specifying how they will be supported to ensure that they do not have an inappropriate caring role which adversely impacts on their life chances.

Our Vision

Carers will be universally recognised, valued and supported with information, advice and support to enable them to have better health and wellbeing.

Support will be tailored to meet individual needs enabling Carers to maintain a balance between caring responsibilities and leading a fulfilling life outside of caring.

Our desired outcomes:-

1) Carers are recognised, and valued
2) Carers can enjoy life outside their caring role
3) Carers have better health and wellbeing and are supported to make this a priority
4) Carers are supported to realise their potential
5) Carers are supported to enable them to maintain and sustain their caring role
The National and Local Picture

In recognition of the growing demands for care and support, recent years have seen a number of laws and commitments introduced that raise the profile of Carers and give them a range of legal rights. It is in this context that our Carers Strategy 2015-18 will apply, ensuring that Carers receive the support they are entitled to and that their valuable contribution is recognised, appreciated and that they are supported to maintain their caring roles in a way that considers their own wellbeing as well as that of the person they are caring for leading to preventing delaying or reducing the need for higher level care.

CARE ACT 2014

The Care Act replaces much of the existing legislation for people that are being cared for and those who care for others. It became law in 2014 and most of the Act came into force in April 2015, with the rest following in April 2016. This strategy is driven by the requirements set out in the Care Act 2014 which places a new duty to promote wellbeing and take on new functions to ensure that people:

- Receive services that prevent, reduce and delay their care needs from becoming more serious
- Can get the information they need to make good decisions about care and support

Assessments, Eligibility and Support Planning

All Carers are now entitled to a Carer’s assessment where the Carer has an appearance of need and are entitled to support if they meet the national eligibility criteria. The eligibility decision-making process for Carers with support needs involves the consideration of the following three criteria:

- Do the needs arise because the Carer is providing necessary care and support?
- Is the Carer’s physical or mental health affected or at risk of deteriorating, or is the Carer unable to achieve any of eight specified outcomes?1
- Is there consequently a significant impact on the Carer’s wellbeing?

While the Care Act deals predominantly with adult social care, it makes new provisions for the Carers of disabled children who are approaching their 18th birthday to get a Child’s Carer’s Assessment (CCA) ‘in transition’ and Young Carers caring for an adult.

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1 Carrying out any caring responsibilities that the carer has for a child; providing care to other persons for whom the carer provides care; maintaining a habitable home environment; managing and maintaining nutrition; developing and maintaining family or other significant personal relationships; accessing and engaging in work, training, education or volunteering; making use of necessary facilities or services in the community; engaging in recreational activities
The wellbeing principles are also part of the eligibility criteria. As a local authority, NCC has to consider the impact of a person’s role as a Carer on their wellbeing. If the impact is significant then the eligibility criteria are likely to be met. When the assessment is complete, a decision will be made as to whether the Carer’s needs meet the national eligibility criteria.

Carers with eligible needs will have a support plan developed to meet their needs which will be agreed with the County Council. Carers’ support needs can be met through community, prevention and Carers-commissioned support or a direct payment that will only be offered if the support available can not meet the assessed unmet eligible need.

**CHILDREN & FAMILIES ACT 2014**
The Children and Families Act 2014 covers support for children and young people who may be Young Carers, and for disabled children receiving care and their families. The Act gives Carers under the age of 18 the right to an assessment on the appearance of need – they do not have to request one. It also requires local authorities with social care responsibilities to assess whether Parent Carers within their area have support needs and, if so, what those needs are. The local authority must ask the parent, the disabled child if possible, and any other children the parent has, for their views. The requirement that Carers provide a substantial amount of care on a regular basis in order to be assessed has been removed as part of the Act.

**PERSONALISATION AGENDA**
Personalisation means enabling people to make meaningful choices and to take control of their support arrangements, regardless of service setting or how their personal budget is managed. The Care Act gives local authorities a new legal responsibility to provide a support plan for Carers. For the first time, the Act provides people with a legal entitlement to a personal budget, which is an important part of the support plan. The personal budget must be included in every plan, unless the person is only receiving intermediate care or reablement support to meet their identified needs. Even when an assessment says that someone does not have needs that the local authority should meet, the local authority must advise people about what needs they do have, and how to meet them or prevent further needs from developing. This means recognising and supporting Carers in their role, while enabling them to maintain a life beyond their caring responsibilities.

We recognise that every Carer’s situation is unique and requires a personalised approach to provide the right support that can meet the needs of both the Carer and the person they care for.

**Local Authority and Health Resource Position**
Locally, the environment in which we work is also changing. Local government and Clinical Commissioning Groups across the country have experienced significant budget reductions and this means it is more important than ever that Northamptonshire County Council and Nene and Corby CCG’s works in partnership and works differently to ensure it can deliver what the Carers of the County need.
The Carers Partnership for Northamptonshire is made up of statutory authorities, voluntary and community organisations that provide Carers’ support services, and Carers and former Carers themselves. Working in partnership is vital to make sure we join up services so that Carers are not left wondering who they should turn to for support, and to maximise the funding available to support Carers in their role.

**NHS Responsibilities**

NHS England has a number of responsibilities towards Carers that have been outlined in the NHS Outcomes Framework and within NHS England’s Business Plan and Planning Guidance. One notable objective in the mandate and business plan is “to ensure that the NHS becomes dramatically better at involving patients and their carers, and empowering them to manage and make decisions about their own care and treatment”. Carers should be fully and appropriately involved in the discharge of the care for person from acute settings, not put under pressure and allowed adequate time to decide on their future caring role. This forms the basis of the NHS Commitment to Carers².

In addition, the NHS Outcomes Framework (2014/15) incorporates an indicator that seeks to measure the health related quality of life for carers. This recognises that poor Carer health as well as affecting the well-being of the individual Carers, impacts on the workload of GP services, and increases unnecessary admission to acute services.

Finally, as part of the NHS Five Year Forward View, the NHS has committed to four actions to engage with communities and citizens to involve them directly in decisions about the future of health and care services:

- Better support for Carers
- Creating new options for health-related volunteering
- Designing easier ways for voluntary organisations to work alongside the NHS
- Using the role of the NHS as an employer to achieve wider health goals

The NHS intends to work with Carers’ organisations to support new volunteer programmes that could provide emergency help when Carers themselves face a crisis of some kind, as well as better matching volunteers to the roles where they can add most value. The Forward View makes the case for a more activist prevention and public health agenda: greater support for patients, Carers and community organisations and new models of primary and out-of-hospital care.

**Funding To Deliver the Strategy**

The Better Care Fund has been introduced to support transformation and integration of health and social care services to deliver better outcomes and greater efficiencies. This is a pooled budget that shifts resources into social care and community services. It is anticipated that Northamptonshire

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County Council will be lead commissioner for support to help the delivery of this strategy with a combined fund.

With the introduction of the Care Act we will need to balance the distribution of support we offer to Carers with the need to provide personal budgets\(^3\) and support the continuation of preventative and community support which will be accessible to all Northamptonshire Carers and meets their needs.

The Northamptonshire Carers Model is based on the principle that if Carer’s eligible support needs can be met through community, prevention and Carers-commissioned support then the local authority will have discharged its responsibility. A direct payment will only be offered if the support available can not meet the assessed unmet eligible need.

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\(^3\) A personal budget refers to the support that is provided to the Carer – this can be commissioned support only, a mix of commissioned support and a direct payment, or a direct payment only depending on the eligible needs of the Carer.
Who are Northamptonshire’s Carers?

There has been a considerable increase in the number of Carers in the county. The number of people who described themselves as a Carer in the 2011 Census was 69,498, an increase of almost 10,500 (18%) since the previous Census in 2001. This included a 27% increase in East Northamptonshire and a 23% increase in Daventry. The figures for the county equate to almost 10% of the population performing a caring role. We also saw from the Census data that the number of Carers caring for more than 50 hours per week has risen sharply. Almost 15,000 people stated that they were providing 50 or more hours of unpaid care per week, and approximately 3,000 of these work full time. In contrast, around a quarter of our caring population are retired but this indicates that they could soon need care themselves. (A fuller breakdown of statistics can be found in Appendix 1).
National survey data tells us that Carers report that caring has a negative impact on their physical, emotional and economic wellbeing. They often do not prioritise their own health and miss routine health appointments and check-ups with doctors and dentist due to their caring responsibilities.

We understand that our Carers’ population has grown, just as the population of those who need care has grown too. However, Carers are a very diverse group and while they may share many of the difficulties, they will have different experiences depending on their circumstances. Therefore, this strategy looks at the types of Carers rather than the condition or illness of the cared for person to understand their particular challenges.

Information about the number of Young Carers in Northamptonshire is limited and it is an area we need to understand more fully. A separate strategy will be developed to explore in more detail the requirements for Young Carers and the duties placed on local authorities by the Children & Families Act 2014.

Parent Carers may be balancing caring for a disabled child with other childcare responsibilities. This is why Parent Carers are also entitled to an assessment on the appearance of need, and why the assessment should take into account the need to safeguard and promote the welfare of the disabled child cared for and any other child for whom the Parent Carer has parental responsibility. They may also have to make the choice between caring and working, meaning that the family may experience financial hardship as a result. 52 per cent of families with a disabled child are at risk of experiencing poverty, and it costs up to three times as much to raise a disabled child, as it does to raise a child without disabilities⁴. In addition, isolation is a common feeling amongst Parent Carers, who feel discriminated against because of the stigma they experience, and because they may not be able to participate in activities that other families participate in⁴.

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⁴ Carers UK: Forgotten Families – The Impact of Isolation on Families with Disabled Children Across the UK (2011)
‘Sandwich Carers’ may be caring for elderly parents as well as still raising children of their own, trying to juggle professional life. They may feel torn in several directions, leaving even less time for themselves or their relationships. Depending on the support available for the person being cared for, this can involve travelling and dividing life between two households to support. Working can also prove difficult and the need for an understanding and sympathetic employer is vital, or the risk that the Carer must give up work becomes a reality.

In terms of Older Carers, the 2011 Census showed that there were almost 14,500 Carers over the age of 65 living in Northamptonshire (21% of the total number of informal Carers). They may be caring for spouses, or, in smaller numbers, siblings, older parents, or adult children with disabilities. Since older age groups are increasingly in need of care and support themselves, there is a greater risk that these caring roles will break down and that both the Carer and the cared for person will require care and support from an external provider. National research shows that Older Carers providing 20 or more hours of unpaid care a week are more likely to report that they are in ‘not good’ health.

In a review of the evidence on family structures and care, the Centre for Policy on Ageing (on behalf of Age UK) found that family size is getting smaller and the care of older people by their children and their children’s spouses is likely to decline. At the same time, gains in life expectancy for men mean there are a falling number of widows and there are more spouses and partners who are available to provide care. This suggests that the shift towards caring in later life will continue as more care is provided to people in older age by other older people, often their spouse or partner⁵. They are more likely than any other Carers to be caring around the clock, with the resulting pressures that this situation creates. The next step on from this is where people are Mutual Carers, in the sense that they both provide some element of care to each other, with all the risks that such a situation presents in terms of the likelihood that one of the caring roles breaks down. Being a Mutual Carer does not just affect Older Carers, Mutual Carers may also be younger adults who may have for instance mental health or substance misuse issues and mutually support each other.

Within these categories of Carers, it is important to remember that diversity means that not everyone of each ‘type’ of Carer will have the same experience.

National research shows that BAME (Black, Asian and Minority Ethnic) Carers provide more care proportionately than White British Carers, putting them at greater risk of ill-health, loss of paid employment and social exclusion. Certain groups also experience greater levels of isolation, namely Pakistani and Bangladeshi Carers⁶. They can also face additional barriers, for instance cultural barriers, stereotypes and language which can increase the chances of poorer health, poverty and social exclusion. BAME groups are more likely to be caring for a sick or disabled child, especially for an adult disabled son or daughter aged 20 to 24 – which reflects long term and enduring caring responsibilities and are more likely to be caring for someone with a mental illness.

⁵ Carers UK: Caring into Later Life (2015)
⁶ Carers UK: Half a Million Voices (2011)
Other national research has shown that LGB&T (Lesbian, Gay, Bisexual and Transgender) Carers and individuals often experience discrimination and marginalisation that impacts upon their ability to access services and receive the most appropriate support\(^7\). Evidence gathered through the survey on Adult Social Care shows that only 4% of LGB&T people surveyed felt they were able to balance their caring responsibilities with their own quality of life, with the majority (64%) feeling that they couldn’t balance the two together.

This shows that while Carers experience many common themes, it is important to acknowledge the different experiences that they will have and to ensure all Carers in Northamptonshire are supported in a way that is appropriate to their needs.

\(^7\) The Adult Social Care Outcomes Framework: Lesbian, Gay, Bisexual and Trans Companion Document
**What are our Carers telling us?**

The Survey of Adult Carers is a biennial statutory survey, carried out by local authorities. The 2014/15 survey included additional questions that Northamptonshire County Council included to find out about Carers’ knowledge of information and advice on services, where Carers perceive service gaps to be and Carers’ knowledge of the Care Act 2014. A detailed analysis can be found in Appendix 2.

This information, along with feedback from focus groups, Carers Partnership Board and postal consultation has been used to shape this strategy highlighting the need to deliver improvements in:

- Quality of life of Carers
- Satisfaction with services
- Carers to be involved with discussions about the person they care for
- Greater control over their daily lives
- Support to increase social contact and reduce social isolation
- Improved advice, information and support and access to it
- Services for working Carers
- One to one support to help navigate the health and social care systems and provide emotional support
- A diverse range of respite opportunities
- Concerns from Carers about what happens to the cared for person after their death

Carers also told us that they valued:

- Voluntary services that offer support
- Information, advice and the helpline
- Respite services, support groups and activities
Our Model of Support for Carers

Our model of support for Carers invests in a preventative approach and aims to prevent, reduce or delay the need for care and to maintain and sustain the caring role. The model (Figure 1) is presented in four elements, but this is not a progressive model as Carers will be able to access support from different interventions depending on their needs and eligibility.

The Four Elements Explained (figure 1)
**Level 1: Universal Support for Carers**

Carers will receive general advice, information and signposting about Carers issues from a range of commissioned and community support services helping people to identify themselves as Carers and signposting to a range of services that can help them to maintain personal interests or activities and find easily accessible advice and support about the person they are caring for. This could be through the Carers support or through the Wellbeing CIC service which is being developed in Northamptonshire.

**Level 2: Targeted Preventative Support for Carers**

This will cover more preventative activities e.g. Carer Cafes, peer support helping Carers to support each other and help to maintain and sustain the Carer in their Carer’s role providing some low level support around their health and wellbeing.

**Level 3: Targeted low level Carer Support**

This represents more focused Carer’s activities that provide interventions with a short term input to manage a particular situation and helps to avoid the breakdown of the caring role.

**Level 4: Targeted High Level Support for Carers**

This element of the model involves a more statutory assessment of need against eligibility criteria. Adopting a person-centred approach which assesses the strengths of the Carer will be supported to make the best use of their circle of support and local support which will focus on maintaining their health and wellbeing and sustaining the caring role. Currently there are approximately 3,800 Carers who have previously been assessed and receive support.

Our strategy is committed to responding to the implications of the Care Act and meeting the needs of Carers. Our preventative approach will ensure that high quality accessible information, advice and support are available to help Carers plan for their needs.
What outcomes do we want to achieve for Carers?

**Vision**

Carers will be universally recognised, valued and supported with information, advice and support to enable to have better health and wellbeing.

Support will be tailored to meet individual needs enabling Carers to maintain a balance between caring responsibilities and leading a fulfilling life outside of their caring role.

**Key Outcomes**

- Carers are recognised, and valued
- Carers can enjoy life outside their caring role
- Carers have better health and wellbeing and are supported to make this a priority
- Carers are supported to realise their potential
- Carers are supported to enable them to maintain and sustain their caring role

**Priorities**

1. Identification of Carers
2. Information, advice and signposting
3. Recognition and feeling valued

1. Support for working Carers
2. Enjoying some leisure time
3. When the caring role ends

1. Prevention and early intervention
2. Breaks for Carers
3. Health and wellbeing

1. Employment, training and volunteering
2. Improved commissioning and market development
3. Supported to identify and maximise their income
4. Improved engagement
5. Achieving equalities

1. Carers assessments
2. Carers Support planning
3. Personal Budgets
4. Helping Carers to maintain their caring role
5. Specialist, targeted training to empower Carers
We will achieve this by:

- By providing high quality, easily accessible information, advice and support which is timely and appropriate
- By delivering a range of preventative services that will delay, prevent or reduce the need for more intensive support
- Support Carers to develop emergency plans that help them to cope in a crisis
- Support Carers to consider and address their own health and wellbeing
- Intervention support that is timely and short term when needed with the aim of supporting the Carer to sustain their caring role independently
- Carrying out quality statutory Carers’ assessments to identify eligible support needs and a support plan that enables the Carer to maintain their caring role on a long term basis as required
- Having adequately trained assessors and supporters who are able to offer expertise and support to the diverse range of Carers in the County
- Developing the “Supporting Working Carer” pilot to support working Carers to maintain their caring role and employment or return to employment after their caring role ends

Key to achieving this will be:

- Continuing to work in partnership with our partners facilitated via the Carers Partnership Board with a commitment from everyone to identify, value and support Carers
- Identify and maximise resources to add value to commissioned services
- Develop a quality framework for our Carers support to drive up and measure quality
- Commissioning support for Carers for statutory assessments, support planning, preventative services and direct payments
- Effective information sharing and shared systems
- Ensuring all developments are Carer guided and facilitating active engagement in the coproduction of support
- Ensuring safeguarding is a priority for Carers and the person they care for

Measuring our Success

We recognise that we have come a long way since our first Carers Strategy in 2010, however we also recognise that there is still a lot of work to be done to achieve the vision set out in this strategy. The implementation will set out “what success looks like” and will be monitored through the Carers Partnership Board and contractually through the commissioners.

Implementation Plan
To be developed with new providers, Carers and the Carers Partnership Board following the tender process.
Appendix 1

Key Facts about Northamptonshire Carers from the 2011 Census

- Population
  - 10% of the Northamptonshire population are informal Carers

- Caring Commitment
  - 67% care for 1-19 hours per week
  - 21% care for 50+ hours per week
  - 12% care for between 20 and 49 hours per week

- Age
  - 72% are 25-64
  - 21% are over 65
  - 7% are under 25

- Ethnicity
  - 94% are White
  - 3% are Asian/Asian British
  - 2% are Black/African/Caribbean/Black British
  - 1% are Mixed/Multiple

- Gender
  - 58% are female
  - 42% are male

- General Health
  - 74% report having good or very good health
  - 20% report having fair health
  - 6% report having bad or very bad health

- Economic Activity
  - 58% are in employment
  - 38% are economically inactive
  - 4% are economically active but unemployed.

Meanwhile, the significant demographic changes within the county that have taken place and will continue to do so have implications for our current Carers and those who may need to provide care in the future.

- Over 14,000 residents are aged 85 years and over, which was an increase of 33% between 2001 and 2011 – projected population change estimates that the over 85 age group will increase by a further 25% by 2021.

http://www.northamptonshireanalysis.co.uk/dataviews/view?viewld=199
The growth within the over 85s and the difference in life expectancy between men and women will also lead to a greater number of people living alone who may require care and support from someone they do not live with.

While not exclusively so, this age group has a tendency to live in the less densely populated areas of the county – this presents a problem not only around access to services and dependence upon informal Carers but also around the impact of isolation on both physical and mental health for them and their Carer.

Significant improvements in the lifestyle and quality of life have contributed toward people having longer lives and staying healthy for longer, but a prominent issue exists around the extent of support demands amongst this group, particularly as they become more frail and vulnerable from the age of 85 on.

There are more instances of age-related illness, such as dementia, stroke and diabetes – just over 8,000 people had dementia in 2014 and this is predicted to almost double by 2030.

As at the last Census (2011) an estimated 112,000 people, or 16% of the population had some form of disability or long-term illness which restricted their day-to-day activities – this increased to almost 85% of the over 85s population.

National research estimates the prevalence of disabilities in children at between 3% and 5.4%. This means that between 4,405 and 7,928 children in Northamptonshire have some form of disability. However, based on households’ self-assessment, the numbers of children living with a disability of long-term illness are much higher, at over 30,000 children and adolescents. Clearly there are wide variations between these figures, and this demonstrates the difficulty of getting accurate data when there is also such a variety of conditions included in the definition.

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9 2014 JSNA Demography Chapter
http://www.northamptonshireanalysis.co.uk/bytheme?themeld=35&themeName=JSNA&type=Resources

10 As above

11 As above

12 Children and Maternal Health Intelligence Network,
http://atlas.chimat.org.uk/IAS/profiles/profile?profileId=44&geoTypeld=4
Appendix 2

The Survey of Adult Carers

The Survey of Adult Carers is a biannual statutory survey, carried out by local authorities. The 2014/15 survey included additional questions that Northamptonshire County Council included to find out about Carers’ knowledge of information and advice on services, where Carers perceive service gaps to be and Carers’ knowledge of the Care Act 2014.

On a positive note,

- 61% of respondents were at least quite satisfied with the services that they had received
- 85% of respondents were at least reasonably happy with how they spend their time
- 84% said they had at least some control over their lives
- 87% of respondents suggested that they had no worries about their personal safety
- More people accessed information and advice, and more people found it at least fairly easy to find (51% in 2014/15 compared to 43% in 2012/13)
- The advice was found to be more helpful in 2014/15 compared to in 2012/13. More people found it to be very helpful (2% more) and more people found it to be quite helpful (4% more)

However, the responses also identified areas for improvement:

- Carers reported quality of life has worsened by 1.56%. This is based on the results of 6 questions about Carers’ lives
- Overall satisfaction has on the whole decreased (61% at least quite satisfied compared to 69% in 2012/13)
- Less people felt involved in discussions about the person they cared for (40% felt at least usually consulted compared to 48% in 2012/13)
- 16% of respondents said they had no control over their daily lives (a 3% increase from in 2012/13)
- 16% of thought that they were neglecting themselves (this is the same amount as in the 2012/13 survey)
- 18% said that they had little social contact with people and feel socially isolated (this is a 1% increase from 2012/13)

On advice and information, Carers commented on:

- the need to know what information to look for before they could find it
- finding it hard to find information and advice out of work time
- delay in response times from a variety of organisations to requests for assistance
- poor co-ordination of services
- access to services especially for Northamptonshire’s rural communities and small villages/towns
• conflicting and confusing information provided
• difference in the quality of information and advice given to those that are self-funding and financing
• confusing welfare benefits advice
• complexity of the caring role
• a mixed view about organisations and services that assist them
• key points of access for information within the community
• the range of communications formats for information and advice
• the cared for not wanting to seek advice and information which then compels the Carer to cope with the situation of caring in not an efficient manner

On service gaps, Carers commented on:
• access of services
• wanting a range of activities offered
• the range of mental health wellbeing that can affect the level of support the Carer is able to receive
• emotional support and the need to have someone to talk to
• the range of local services/groups on offer
• staff training and the skills required for identifying when people need help
• services and opportunities for Carers who are in employment
• having to give up employment to care and not be aware of all the services for Carers on offer
• having good and relevant financial advice
• paperwork and form filling and the time it takes
• the availability of support workers and/or someone to contact Carers to ask how they are

On helping Carers to continue caring, Carers commented on:
• respite services
• time off for themselves
• wanting to feel appreciated for the caring they do, often 24/7
• having and maintaining dignity in what they do and for this to apply to whom they care for
• financial security and extra finance
• the quality of staff/professionals including services offered and the standard of those services
• the need for the cared-for to understand the needs of the Carer and for the cared-for to be informed professionally to accept help to assist the Carer

On awareness of the Care Act 2014, Carers commented on:
• not understanding the Care Act
• wanting more information on it
• not expecting their personal circumstances to change as a result
• hoping there would be more support for Carers
• stating that although the Act may read well, practical support is “thin on the ground”