

### Select Committee Debate: Carers Task and Finish Group

#### Introduction

**1** This report summarises the findings of the Carers Task and Finish Group (TFG), set up as a Scrutiny TFG in 2012 to assess whether the support provided in West Sussex to carers of all ages is appropriate and sufficient, and to identify areas for improvement. Now that the TFG has reached its conclusion, its members requested a final debate at a full County Council meeting to consider how to maintain and increase awareness of carers' needs, to raise the profile of carers and to ensure they receive the support they need in all aspects of their lives. Members of the Council are invited to focus on:

- (1) **The TFG's recommendations for future action, set out in this report at paragraph 14 on page 247;**
- (2) **What still needs to be done to support carers, and what the Council can do to both influence and enable this;**
- (3) **How support for carers should be monitored and reviewed in future, given that the TFG has now concluded its work;**
- (4) **The role local councillors can play; and**
- (5) **The message they would like to give the new Council in May 2017 on taking forward the carers' agenda.**

#### **Some key facts<sup>1</sup>:**

- It is estimated that in West Sussex there are over 84,000 unpaid carers, providing support to family or friends and this is expected to increase to 97,000 by 2023
- 16,000 of these are registered carers, receiving some kind of service – ranging from advice and information to a full carers' support package
- Around 70% of all carers undertake caring activities for over a year before they identify themselves as a carer
- There could be as many as 6,000 'hidden' young carers in the county
- There are growing numbers of 'dual carers' juggling work and family caring whilst caring for older relatives
- The economic value of the social care contribution made by Family and Friend carers has been estimated nationally at £119bn per year – which equates to a contribution of just over £1.5bn per year in West Sussex

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<sup>1</sup> *West Sussex Carers Health and Social Needs Assessment (Public Health Directorate, June 2013); The State of Caring (Carers UK, 2013); West Sussex Interagency Carers' Strategy, Commissioning Intentions and Plans, 2010-2015; West Sussex Joint Commitment to Family and Friends Carers 2015-20*

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### Background

2 The TFG's reports are available on the Council website, providing full details of its findings and recommendations:

- Phase one report, April 2013:  
<http://www2.westsussex.gov.uk/ds/cttee/tfg/tfgcarersphase1.pdf>
- Phase two report, December 2014:  
<http://www2.westsussex.gov.uk/ds/cttee/tfg/tfgcarersphase2.pdf>
- Review Findings, December 2015:  
<http://www2.westsussex.gov.uk/ds/cttee/tfg/tfgcarersreviewdec15.pdf>
- Final review – Commitment to Carers (feedback to Health and Wellbeing Board), July 2016:  
<http://www2.westsussex.gov.uk/ds/cttee/tfg/tfgcarersjuly16.pdf>

3 The TFG carried its work out over three phases:

	<b>Focus</b>	<b>Membership</b>
1. December 2012 to March 2013	<ul style="list-style-type: none"> <li>• Integration across all agencies</li> <li>• Access to services</li> <li>• Raising the profile of carers</li> <li>• Communication/information</li> <li>• Transition from Children's to Adults' Services</li> </ul>	Mrs Millson (Chairman) Mr Blampied Mrs Evans Mrs Jupp Mrs Knight Mrs Smith
2. October 2013 to November 2014	<ul style="list-style-type: none"> <li>• Young carers; the impact of the transition process</li> <li>• Mental health issues, including support for carers of people with dementia</li> <li>• The impact of caring on Black and Minority Ethnic communities</li> <li>• The financial impact of caring</li> <li>• Workplace support for carers</li> <li>• Respite (short breaks) and counselling</li> <li>• The role of GPs</li> <li>• Information, communications and training</li> </ul>	Mrs Millson (Chairman) Mrs Duncton Mrs Evans Mr Griffiths Mrs Jones Mrs Jupp Mrs Smith
3. December 2015 to May 2016	<ul style="list-style-type: none"> <li>• Assessing progress against the TFG's previous recommendations</li> <li>• Monitoring and reviewing the implementation of the new West Sussex Commitment to Carers</li> </ul>	

4 Through the course of its work, the TFG has had invaluable input from Carers' Support West Sussex, as well as officers of the Council. It has engaged with, and heard evidence from, a range of individuals and organisations, including: adult and young carers, Adults' Services Customer and Carer Group, Minority and Ethnic Communities Working Group, NHS clinical commissioning groups, groups of GPs in the north and south of the

county, a carer ambassador from Carers UK, the Alzheimer's Society and Sussex Partnership NHS Foundation Trust (the mental health service provider for Sussex).

- 5 It has reviewed a wide range of evidence and information, including updates on the implications of key legislation (the Care Act, the Children and Families Act) and the Carers' Services Strategic Commissioning Review carried out by the County Council. In October 2013 it endorsed the draft West Sussex Young Carers' Strategy, feeding comments into the decision-making process. In May 2016 it reviewed the new [West Sussex Joint Commitment to Family and Friends Carers 2015-2020](#), reporting its findings to the Health and Wellbeing Board, which will be receiving a progress report in November 2016.

### **Key messages from the Task and Finish Group:**

- Many people do not identify themselves as carers, and do not consider they are doing anything beyond providing care and support for their loved ones. But we need to celebrate carers and raise the profile of what they do - recognise the vital role they play and support them to be able to continue to do this. Many carers – and particularly young carers - are 'hidden' and are not known to the different agencies that could help them. We need to identify carers, so that they can be signposted to information and support to help them avoid crisis, and to help them cope when the needs of their cared-for grow.
- There has been significant progress in terms of support for carers since the TFG began its work in 2012; the profile of carers has been raised and more carers are now supported than ever before. However, these are challenging times; financial and demographic pressures mean services and budgets are stretched, and health and social care services in particular face growing demand. We must recognise that support for carers is an investment. Without it, carers may not be able to fulfil their role, and the cost to services may end up being much higher. It is therefore important to ensure there is adequate resource to meet increasing demand and to ensure that assessed needs can be met.
- The service offered by Carers' Support West Sussex needs to be highlighted and publicised by all agencies, particularly by GPs, health and wellbeing hubs and social workers. If people can be referred to Carers Support early, then they can help avoid crisis by being supported to obtain the right information, support, benefits and services.
- It is not just about health and social care: we need to think about providing the right housing and infrastructure to meet people's needs as their circumstances change and about how we ensure we have the right workforce to provide care and support. Workplace support for carers in employment can help them stay in work and avoid financial hardship (as well as social isolation) – and employers will benefit in the long-run from a loyal and stable workforce.

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- There are real opportunities for the Council, working in partnership with other organisations, to provide leadership, be a catalyst for change and find creative solutions to the problems carers face. Local councillors also have a key part to play, helping to raise the profile of carers' issues, understanding what being a carer means, what help is available and encouraging more people and organisations to '**Think Carer**'.

### Summary of the Task and Finish Group's key findings and recommendations

- 1. Raising the profile of Family and Friend carers and building a carer-friendly society:** Like all people, carers need and deserve a good quality of life. We need to ensure that everyone understands the role carers play – and carers themselves should feel valued and able to care for their loved-ones without going into crisis. It costs more for everyone when crisis happens – for the carer and their cared-for; for employers and for health and social care services. We need to help carers build resilience, and enable them to cope with their caring responsibilities by ensuring they know about information and support - and to remove many of the barriers they face, like lack of recognition as partners in care, issues of patient/carer consent to data sharing, IT systems that do not talk to each other and the confusion of different contact numbers and sources of information for the same services.
- 2. Information and support for carers:** The TFG welcomed the fact that there is now one countywide service providing support and information for carers. As the single point of access, [Carers' Support West Sussex](#) is playing a vital role in identifying carers, assessing their needs and helping them to find the right support and information. The development of the '[Connect2Support](#)' website for people needing support in West Sussex is also providing key information on local and national products, services and advice. But more needs to be done to signpost carers to the support and information available, so that they can make the right choices at the right time – and without a complicated referral pathway. A key concern for carers is around confidentiality, and there is a need for information-sharing protocols, to help staff across health and social care feel confident in terms of what they can and cannot do, particularly at times of crisis. There is potential to make better use of Council communications (e.g. through West Sussex Connections and social media) and for County Councillors to act as a voice for their residents who are carers and to help raise the profile of carers' issues.
- 3. Identifying 'hidden' carers:** The fact that many people do not consider themselves to be carers makes it difficult to identify the point at which carers need support. Many carers therefore remain hidden and do not access the support available until the caring role starts to have a detrimental impact on their own lives, such as poor attendance at school, being unable to remain in paid employment, or suffering ill health themselves. Efforts to uncover these hidden carers need to be accelerated, and carers signposted to the support available.
- 4. Young carers** need to be identified and supported, so that they can achieve the same life opportunities as their peers. Significant effort is being made in

West Sussex, within a context of limited resources, to address the needs of young carers and provide them with support and activities, but more needs to be done. Schools, colleges and universities should have processes in place to identify young carers and ensure they have access to adequate support to enable them to have the same opportunities and choices as those without caring responsibilities. Young carers need to be able to influence and help shape the support and services available to them. There is a need to raise the profile of young carers and the issues they face – particularly with schools and colleges and their peers, and work to remove any stigma that young carers may feel as a result of their caring responsibilities, and enable them to discuss their needs and any problems they face without fear.

- 5. Preparing for adulthood:** Significant progress has been made by the Council in addressing the issues young people face through the transition to adulthood, when they reach age of 18 and find that their support arrangements change. The TFG was particularly impressed with the fact that this work has been developed through co-production with parent carers, young people and professional/practitioners. Services have now been developed to span the ages from 0 to 25, so bridging the gap between childhood and adulthood, alongside initiatives such as the Preparing for Adulthood Programme and the Young Adults Carer Service.
- 6. Working better together:** The key to improving support for carers is through partnership working: There is a considerable amount of good work going on across West Sussex to support carers; but more will be needed to underpin prevention and wellbeing agendas. The TFG is realistic about the financial, demographic and legislative pressures on all organisations that can make providing additional support or services difficult. But it believes that a big difference could be made if organisations worked together more – by providing joined-up services that pool resources, skills and expertise and share ideas and best practice, to reduce duplication and costs; by adopting a whole-family approach in relation to health and social care customers, to recognise the support provided by carers, ensuring that both the cared-for and the carer are signposted to the support available; by addressing barriers to data sharing between the NHS and local councils.
- 7. The role of GPs:** A constant theme running throughout the TFG's work has been the key role played by GPs in identifying and supporting carers and in referring them on to information/services. GPs and their teams are often the first point of contact for carers and their cared-for. GP practices have a very heavy and complex workload and it can be difficult to identify patients as carers – particularly when they may not even recognise themselves as carers. There is some good practice in GP surgeries, but this needs to be shared and spread across the county, so that carers are consistently identified and referred to Carers' Support West Sussex as a single point of contact. There should be a nominated Carer Champion/Lead Person in every GP practice and all practitioners should consider and treat carers as 'expert partners in care'.
- 8. Mental health issues, including the support for carers of people with dementia:** The TFG welcomed the range of services available to support

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carers of people with mental health issues, and to help avoid carers developing mental health issues themselves due to their caring responsibilities. However, it was of concern that the carers' experience is often one of loneliness and isolation, and that more still needs to be done. Members were particularly concerned about the volume of need, given predicted levels of dementia diagnosis in the future. This problem has been consistently raised over recent years and local market development should continue to be supported to extend choice of access to opportunities for short breaks. This will help to sustain the increasing number of dementia carers. If caring for someone with mild to moderate memory loss of dementia is seen as a 'normal' family situation and carers are always put in touch with an offer of support for planning ahead, then dementia will be 'normalised' within our dementia-friendly communities. Carers will then more readily and easily access and accept support. GPs and mental health services should be ensuring patients with mental health needs/dementia have annual reviews and that they identify carers and offer them assessments of their need.

**9. The impact of caring on minority ethnic communities:** The TFG supports the development of person-centred approaches and treating people as individuals, whilst at the same time ensuring that culturally appropriate services are available. The focus should be on improving support for all carers, whatever their background or community. As with all the other issues reviewed by the TFG, the importance of clear, coherent and co-ordinated information and advice was highlighted and members felt that the potential to develop better data on minority ethnic communities and improved engagement with carers from minority ethnic communities should be explored. There should also be greater encouragement to recruit volunteers and carers from within the minority ethnic communities, and to provide relevant training for communities to help them support their loved ones.

**10. The financial impact of caring:** Different carers can face different costs. Carers UK's research indicates that carers are likely to report higher utility bills, have higher transport costs and that many carers cut back on essentials like food and heating. 42% of carers have missed out on financial support as a result of not getting the right information and advice. Many carers have given up work at some point to care for loved ones, or have reduced their working hours. However, the TFG heard that personal budgets (direct payments) have had a significant impact; enabling carers to choose the type of support they need. The TFG highlighted a number of areas to be explored further, including ensuring that the right financial information and advice is locally available and further support for people using direct payments.

**11. Workplace support for carers:** Nationally, it is estimated that more than three million employees currently have to balance their work commitments and their family caring responsibilities. One in five carers give up work to care full-time. Businesses often lose experienced staff, as most carers fall into the 45 to 64 age range. It has been suggested that better support for working carers would save taxpayers £1.3bn a year. The TFG welcomed the lead being taken by the County Council in terms of being a carer-friendly employer – and particularly the development of written guidance for staff and managers and the development of a carers' passport tool. It suggested that

the County Council could influence other employers across the county to develop carer friendly employment practices. It also asked for consideration to be given to requiring providers of outsourced services to make a commitment to carer-friendly employment practices through the contractual process.

**12. Respite (short breaks):** Throughout its work, the TFG has heard from carers of all ages of the importance of respite (or short breaks), to enable a break from their caring responsibilities. For example, for young people this gives them the opportunity to maximise their involvement with education, sports, cultural, social and leisure activities. But the TFG recognised that it is also important for carers to be able to go on breaks and activities with their cared-for, as meaningful activities for the cared-for also mean that the carer has a break. The County Council has a key role to play in the market development of short breaks, and the TFG supports work underway to ensure that the right short breaks are available for carers.

**13. Training** has the potential to help improve awareness and understanding of, and support for, carers. But it is also needed to help carers themselves (e.g. training in manual handling). The TFG would like to see clear training programmes in place for health and social care professionals (GPs, nurses, care assistants, personal assistants, social workers, nursing/care home staff) – but also in schools, for teachers and students. Too often a lack of awareness and understanding can lead to poor quality support for carers.

**14. West Sussex Joint Commitment to Family and Friends Carers 2015-2020:** This [document](#) is a public commitment, produced by the County Council and the three West Sussex Clinical Commissioning Groups, which sets out how organisations will work together to identify and support carers in West Sussex. The TFG reviewed this in May 2016 and recognised that it was beginning to have an impact – but that there was still more work to be done. There were massive challenges in terms of achieving all that was set out in the Commitment – but it was the right direction of travel. The profile of carers had been raised, but there was no room for complacency, particularly in terms of identifying carers and ensuring they were able to access appropriate information and support at an early stage to avoid crisis. Members recognised that it will take time for Think Carer and carers' needs to be fully embedded in all services. For the future, the TFG identified the following key recommendations for future action:

- (a) Services should continue to be monitored and evaluated, with the impact of different approaches assessed: there needs to be continuous audit – particularly for young carers.
- (b) Services need to join up and be based on the needs of the customer (carer/cared-for): there is still more to be done in terms of the integration of health and social care services.
- (c) The role of GPs is key and there may be a need for training of GPs and their staff, particularly in terms of recognising friend and family carers and also in how to evaluate and communicate the consequences of some treatments/medication (e.g. that may impact on the behaviour of the cared-for).
- (d) We need to find community-based solutions to meet the needs of

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- carers and their cared-for, including through innovative approaches to the use of community assets (such as Adult Day Centres), and a more joined-up approach to the use of public buildings.
- (e) Raising the profile of carers continues to be a key priority – and Members should act as champions for carers’ issues and ensure their needs are reflected through the democratic process and the decisions the Council takes.
  - (f) Support for carers in hospitals has not always been positive, and there is more work to do, particularly in terms of the discharge process. There should be training for all A&E staff in dementia awareness and recognition and understanding of carers. There is also a need to ensure carers are supported when the people they care for are in hospital.
  - (g) It is important that adequate resources are provided to ensure that assessed needs can be met. There is a strong economic case for providing carer support.
  - (h) The potential for technology to support innovative solutions to supporting carers needs to be pursued (including through the use of telecare).

### **Some key outcomes/areas of influence of the TFG’s work:**

- Helping to raise the profile of carers and carers’ issues across West Sussex and supporting work to increase the voice of carers – including through highlighting the work of Carers Support West Sussex.
- Sponsoring three debates on carers at full Council meetings and recommending the creation of the Member Carers’ Champion role.
- Lobbying the Council, NHS and other agencies for change – including through improved workplace support for carers; breaking down barriers to data sharing; identifying clear named carer leads in GP practices; ensuring the commitment to extending the Memory Assessment Service to all patients with a dementia diagnosis was fulfilled.
- Influencing commissioning plans and plans for future service provision, including through inputting into the development of the Young Carers’ Strategy (2013-15) and the West Sussex Joint Commitment to Family and Friends Carers (2015-20).
- Carer engagement forums across the county have been reviewed
- Reference to carers to be made in the Council’s Equality Impact Reports that accompany key decisions.
- All schools and chairmen of governors have been written to, ensuring they are aware of the need to meet the needs of young carers and to signpost them to support services.
- E-learning modules on identifying and supporting carers have been developed for the health and social care workforce.
- County Local Committees have publicised the Commitment to Carers through meetings and social media.
- A commitment by NHS clinical commissioning groups’ to reviewing and implementing the TFG’s recommendations within their work – including seeking to persuade their primary care colleagues to actively identify carers within their practices and to signpost them to carers’ support services.

- The introduction of annual mental health reviews within Sussex Partnership NHS Foundation Trust and GPs to ensure patients and carers with mental ill-health/dementia have appropriate assessments and matched support.

### Recommended

Members are invited to note the TFG's achievements and to endorse the recommendations for future action set out in this report.

### Morwen Millson

Chairman of the Carers Task and Finish Group

### Task and Finish Group Members:

Mrs Janet Duncton	Mrs Amanda Jupp
Mrs Margaret Evans	Mrs Morwen Millson (Chairman)
Mr Peter Griffiths	Mrs Brenda Smith
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### Background Papers

None