August 2020

The economic benefits of short breaks for families of children with life-limiting and life-threatening conditions

In association with volunteers from Compass Lexecon

PRO BONO ECONOMICS

together for short lives

Julia's House
Dorset & Wiltshire Children's Hospices

About

Pro Bono Economics enables professional economists from across the private, public and third sectors to volunteer their skills to tackle some of the most pressing issues in society. Working with our network of experienced consultant economists, our volunteers help charities and social enterprises appreciate their economic and social impact and so improve their overall effectiveness. We have worked with over 400 charities across the third sector since our inception in 2009.

Our volunteers from this report are from **Compass Lexecon**, a global economic consulting firms providing law firms, corporations, and government clients with clear analysis of complex issues. Compass Lexecon has been involved in a broad spectrum of matters related to economics and finance – providing critical insight in legal and regulatory proceedings, strategic decisions, and public policy debates.

Disclaimer

This report (the “Report”) has been prepared by Pro Bono Economics ("PBE") based on information provided to it. This information has not been independently verified by PBE. No liability whatsoever is accepted and no representation, warranty or undertaking, express or implied, is or will be made by PBE or any of its directors, officers, employees, advisers, representatives or other agents (together, “Agents”), for any information or any of the views contained herein (including, without limitation, the accuracy or achievability of any estimates, forecasts or projections) or for any errors, omissions or misstatements. Neither PBE nor any of its respective Agents makes or has authorised to be made any representations or warranties (express or implied) in relation to the matters contained herein or as to the truth, accuracy or completeness of the Report, or any associated written or oral statement provided.

The Report is necessarily based on financial, economic, market and other conditions as in effect on the date hereof, and the information made available to PBE as of the date it was produced. Subsequent developments may affect the information set out in the Report and PBE assumes no responsibility for updating or revising the Report based on circumstances or events after the date hereof, nor for providing any additional information.

The Report is not an opinion and it is not intended to, and does not, constitute a recommendation to any person to undertake any transaction and does not purport to contain all information that may be required to evaluate the matters set out herein.

The Report should only be relied upon pursuant to, and subject to, the terms of a signed engagement letter with PBE. PBE only acts for those entities and persons whom it has identified as its client in a signed engagement letter and no-one else and will not be responsible to anyone other than such client for providing the protections afforded to clients of PBE nor for providing advice. Recipients are recommended to seek their own financial and other advice and should rely solely on their own judgment, review and analysis of the Report.

This report and its content is copyright of Pro Bono Economics. All rights are reserved. Any redistribution or reproduction of part or all of the contents in any form is prohibited other than as is permitted under our Creative Commons Attribution – Non Commercial 4.0 International Licence. Under this licence, you are permitted to share this material and make adaptations of this material provided that appropriate credit is given and the material or adapted material is not used for any commercial purposes. Furthermore, you may not apply legal terms or technological measures that legally restrict others from doing anything the licence permits. No warranties are given. The licence may not give you all of the permissions necessary for your intended use. For example, other rights such as publicity, privacy, or moral rights may limit how you use the material. This statement is solely a summary of the applicable licence and is not a substitute for the terms of the licence. For full details of the applicable terms of the licence, refer to the creative commons license.

© Pro Bono Economics [2020]. All rights reserved.

PRO BONO ECONOMICS

Contents

Executive Summary

Pro Bono Economics, in association with volunteers from Compass Lexecon, supported Together for Short Lives and Julia's House to assess the potential taxpayer benefits if all parents who are providing palliative care for children - care for children with life-limiting and life-threatening conditions – are able to access short breaks.

Background

Together for Short Lives estimates that the number of children in the UK with life-limiting or life-threatening conditions is 99,000. There were 86,625 in England 2017/2018[1]. For the purposes of this study, we have estimated that, in the UK, 25,000 children are likely to need palliative care at any one time[2]. Not all children who have life-limiting or life-threatening conditions require palliative care at any one time. However, there is some uncertainty around this number and it is our understanding that Together for Short Lives is in the process of undertaking research to accurately estimate the number of children requiring palliative care. The methodology presented in this report can be adapted to reflect any update to the estimated number of children currently requiring palliative care.

The parents of these children are often the primary carer; facing psychological, physical and social distress due to the responsibilities of their roles.

One of the ways to help carers deal with stress and improve their quality of life is to provide short breaks to those with caring duties. These short breaks allow parents to reconnect with their partners, catch up on work and errands or simply spend time alone, without the immediate need of attention that is often required.

Together for Short Lives is a UK charity which wants to help every child and family living with a life-limiting or life-threatening condition get the very best care and support they can so they can make the most of every moment together. By supporting and speaking up for children and families, and those that support and care for them, Together for Short Lives is driving for a better quality of life and end of life for children with life-limiting and life-threatening conditions.

Julia's House is the Dorset & Wiltshire children's hospices charity which instigated research with Bournemouth University by Mitchell, AJE, in 2017 on the impact of regular respite breaks on parent couple relationships, for parents with a child with a life-limiting or life-threatening condition.

Scope of this study

The aim of our study is to estimate a monetary value for the potential taxpayer benefits if all parents providing palliative care for their children were able to access short breaks. We draw on existing evidence to quantify the impact of short breaks on clinical measures of parent stress and then link this reduction in stress to taxpayer benefits through three key channels:

- **Improved physical health:** Reduced stress leads to improved physical health among carer parents, which in turn leads to reduced number of general practitioner (GP) visits and cost-savings to the health system.
- **Improved mental health:** Reduced stress leads to improved mental health among carer parents, which in turn reduces the use of mental health services and the associated costs.
- **Improved work attendance:** Improved work attendance can be measured in reduced number of sick days taken, which lead to increased productivity and tax revenue.

Our focus on how short breaks reduce costs to public services as a result of stress reduction means that we are likely to underestimate the full scale of the benefits to society. For example, we do not include the potential impact of short

---

[1] Fraser, L., Gibson-Smith, D., Jarvis, S., Norman, P., Parslow, R. (2020) Make Every Child Count: Estimating current and future prevalence of children and young people with life-limiting conditions in the United Kingdom. Final Report – February 2020

[2] The number of children in palliative care in the UK is calculated as the prevalence rate multiplied by the population of children from the Office of National Statistics ("ONS"). The prevalence rate is 16 per 10,000 and is provided by Craft, A., & Killen, S. (2007). Palliative care services for children and young people in England. Secretary of State for Health, p.21. Retrieved from: https://www.nsf.no/Content/662668/PALLIATIVE_CARE_SERVICES_FOR_CHILDREN.pdf on 25 June 2019.

breaks on the in-work productivity of parents, the quality of their relationship, parents' income, discretionary spending, making parents more effective in caring for their children or increases in non-monetary outcomes such as wellbeing.

Furthermore, consideration of the costs of providing short breaks for all parents is outside the scope of this report. The intention of our analysis is to illustrate the cascading impact of how short breaks decrease parental stress, providing an initial indicator of potential economic benefits, specifically for taxpayers.

Key findings

We find that:

- We find evidence that 11.7% of parents of children in palliative care would experience a significant reduction in stress as a result of providing them with short breaks.
- For every parent who experiences a reduction in stress we would expect this to reduce expenditure on GP visits by around £41 and mental health expenditure by around £920 per year.
- For every parent who experiences a reduction in stress we would expect this to reduce the number of days taken off work by around 2-3 days per year.
- The total potential benefits to taxpayers from providing short breaks to all parents of children in palliative care could be in the region of c£5 million per year, based on the assumption that there are around 25,000 children in palliative care in the UK, with parents most commonly acting as their primary carer.

Implications

Our analysis suggests that the benefits from providing short breaks to parent carers extend beyond the parents themselves. Short breaks generate public benefits through cost-savings to the healthcare system and increased tax revenue. Although an examination of the costs of providing short breaks to all parents of children in palliative care is outside the scope of this report, we hope that our evidence can further support the case for helping those parents who are dealing with such demanding and challenging situations.

However, we recognise that this analysis is by no means a comprehensive accounting of the factors that are affected by the provision of short breaks and that there are limitations to the evidence we have been able to use. Future assessments of the potential economic impacts of short breaks for parents providing palliative care would be strengthened by:

- Developing evidence of the impact of short breaks on clinical measures of stress specifically for parents providing palliative care in the UK. At present our study has relied on studies assessing the impact of short breaks on stress for parents caring for severely disabled children in the USA and assumed that the impacts will be similar.
- Assessing the impact of this care directly on the demand for health services such as appointments with GPs and mental health support.
- Building evidence on other, wider impacts so that they can be included, such as the impact on in-work productivity, wellbeing, leisure and discretionary spending.

Adopting a conservative approach

It is our view that the methodology adopted in this report represents a relatively narrow/conservative approach to estimating the potential benefits provided by short breaks. Other methodologies and benefit areas were investigated, but not included due to the difficulties of ensuring robustness. We feel it important to highlight four factors:

- 'Feedback effect' - We have not accounted for the feedback effect among the three channels. For example, to the extent that improved physical health independently leads to a reduction in the number of sick days taken, beyond the impact of reduced stress, this further reduction has not been included in our calculations. Fully accounting for the interactions among the various channels would be a complex exercise, but one which would yield a higher estimate of the public benefits from providing short breaks.

- Other indicators - We have only quantified three channels and one outcome for each channel. Extending the analysis to cover additional channels or additional outcomes would yield a higher estimate of the public benefits from providing short breaks. For example, we recognise that by only including the reduction of GP visits in relation to improved physical health, we only capture one facet of the potential benefits that could accrue in terms of healthcare use.
- Less quantifiable public benefits - Our analysis focuses on quantifiable public benefits such as increased tax revenue and healthcare system cost-savings. Less quantifiable public benefits such as improved wellbeing of the children with life-limiting or life-threatening diseases and their families, long-term health impact, and indirect effects through individual and corporate gain were considered but not included in this paper. Considering these less easily quantifiable public benefits is more difficult, but it would yield a higher estimate of the public benefits from providing short breaks.
- Non-stress channels - By focusing on how short breaks generate public benefits through stress reduction, we have not considered the potential impact of short breaks on increasing parents' leisure time and discretionary spending, making parents more efficient in caring for their children, etc. Accounting for additional means through which short breaks can have a meaningful impact could again yield a higher estimate of the public benefits from providing short breaks.

1. Introduction

This report sets out an economic analysis of the potential taxpayer benefits of short breaks for parents providing palliative care for their children. It was commissioned by Together for Short Lives, a charity who aims for every child and family living with a life-limiting or life-threatening condition to get the very best care and support they can so they can make the most of every moment together.

Background

Together for Short Lives estimates that the number of children in the UK with life-limiting or life-threatening conditions is 99,000. There were 86,625 in England 2017/2018[3]. For the purposes of this study, we have estimated that, in the UK, c25,000 children are likely to need palliative care at any one time[4]. However, it is important to note that this estimate depends on the methodology adopted. We adopt recent research that estimates a prevalence rate of 15 per 10,000 children (0.15%) that 'are living with conditions likely to require palliative care'[5]. This assumption has been adopted in research issued by the National Institute of Clinical Excellence (NICE)[6] which broadly assumes a similar 'prevalence rate' but assumes a lower child population in the UK – leading to a lower estimate of c17,400 children requiring palliative care. It is our understanding that Together for Short Lives is in the process of undertaking research to accurately estimate the number of children requiring palliative care. We note this uncertainty and highlight that the methodology presented in this report can be adapted to reflect any update to the estimated number of children currently requiring palliative care.

The parents of these children are often the primary carer; facing psychological, physical and social distress due to the responsibilities of their roles[7].

One of the ways to help carers deal with stress and improve their quality of life is to provide short breaks to those with caring duties. Examples of short breaks include planned social activities for the child, overnight hospice care and at-home care from healthcare professionals. These short breaks allow parents to reconnect with their partners, catch up on work and errands or simply spend time alone, without the immediate need of attention that is often required.

In addition to the ethical and social significance in providing short breaks, it is also an important topic from an economic point of view. Research on respite care shows the positive impact of short breaks on family outcomes, such as reduced parental stress, improved parent couple relationships, and decreased work absenteeism, amongst others.

In December 2010 the government committed £800 million in funding for short breaks to make sure local authorities could meet their legal duties under The Regulations for Breaks for Carers of Disabled Children 2011 over the course of the Parliament. However, the Every Disabled Child Matters (EDCM) partnership found in 2016 that 58% of local authorities who responded to their freedom of information requests had cut their short breaks spending by an average of 15%[8].

---

[3] Fraser, L., Gibson-Smith, D., Jarvis, S., Norman, P., Parslow, R. (2020) Make Every Child Count: Estimating current and future prevalence of children and young people with life-limiting conditions in the United Kingdom. Final Report – February 2020

[4] The number of children in palliative care in the UK is calculated as the prevalence rate multiplied by the population of children from the Office of National Statistics ("ONS"). The prevalence rate is 16 per 10,000 and is provided by Craft, A., & Killen, S. (2007). Palliative care services for children and young people in England. Secretary of State for Health, p.21. Retrieved from: https://www.nsf.no/Content/662668/PALLIATIVE_CARE_SERVICES_FOR_CHILDREN.pdf on 25 June 2019.

[5] Craft, A., & Killen, S. (2007). Palliative care services for children and young people in England. An Independent review for the Secretary of State. *Department of Health England*, p. 15.

[6] National Institute of Clinical Excellence (NICE) (2016). Resource Impact Report. End of life care for infants, children, and young people with life-limiting conditions: planning and management (NG61)

[7] Craft, A., & Killen, S. (2007). Palliative care services for children and young people in England. An Independent review for the Secretary of State. *Department of Health England*, p. 15.

[8] Why short breaks are our lifeline. Together for Short Lives - https://www.togetherforshortlives.org.uk/short-breaks-lifeline

Scope of this study

The aim of our study is to estimate a monetary value for the potential taxpayer benefits if all carer parents were able to benefit from short breaks. More specifically we use the following definitions:

- Carer parents care for children with life-limiting or life-threatening conditions. These parents often provide economic, clinical and family care to their children above the levels of care provided by parents whose children do not have life-limiting or life-threatening diseases.
- Short breaks refer to respite from caring duties offered to carer parents. Children with life-limiting conditions – and their families – rely on frequent short breaks for respite to enable them to relieve this stress, spend time as a family and do the things that other families do. Every family's needs are different: some need overnight, residential short breaks either with or without their child; some need short breaks for only a few hours at a time, provided at home or in hospital. Some will need a mix of both.
- Taxpayer benefits refer to benefits to the public sector as a result of providing short breaks. This may include cost-savings to the healthcare system as well as tax revenue from increased productivity.

Our approach is guided by three objectives:

- Demonstrate the impact of short breaks on public benefits;
- Rely on robust causal links presented in the relevant literature; and
- Focus on quantifiable public benefits.

After reviewing the current literature on short breaks and holding a discussion with Together with Short Lives and Julia's House to understand how hospice care is provided to children and their families, we arrived at a two-step approach. Firstly, we draw on existing evidence to quantify the impact of short breaks on clinical measures of parental stress. We then link this reduction in stress to economic benefits through three key channels:

- **Improved physical health:** Reduced stress leads to improved physical health among carer parents, which in turn leads to reduced number of GP visits and cost-savings to the health system.
- **Improved mental health:** Reduced stress leads to improved mental health among carer parents, which in turn reduces the use of mental health services and the associated costs.
- **Improved work attendance:** Improved work attendance can be measured in reduced number of sick days taken, which leads to increased productivity and tax revenue.

Our approach, focusing on how short breaks reduce costs to public services as a result of stress reduction, means that we are likely to underestimate the full-scale of the benefits to society. As detailed in the report, we make certain assumptions when direct evidence is not available. For example, we do not include the potential impact of short breaks on the in-work productivity of parents, the quality of their relationship, parents' income, discretionary spending, reduced reliance on state benefits, making parents more effective in caring for their children or increases in non-monetary outcomes such as wellbeing. Based on the considerations above, we have chosen to make conservative assumptions where possible. In addition, assessing the potential costs of providing short breaks for all parents of children in palliative care is outside the scope of this report. However, the intention of our analysis is therefore to illustrate the cascading impact of how short breaks decrease parental stress, providing an initial indicator of potential economic benefits specifically for the taxpayer.

We have chosen to provide unrounded numbers for the purposes of clarity and transparency. However, it is useful to acknowledge that this will not reflect the true level of uncertainty.

Structure of the report

The remainder of the report is structured as follows:

- Section 2 outlines our analytical approach.
- Section 3 provides a summary of our key findings.
- Section 4 concludes the report

2. Our approach

This section provides an overview of the approach used in our analysis.

2.1 Analytical framework

Our analysis is based on empirical findings in the literature on the impact of short breaks on various family outcomes. We identified three channels through which short breaks lead to improved outcomes for parents of children in palliative care:

- Improved physical health of parents
- Improved mental health of parents
- Improved work attendance

These channels are not mutually exclusive; there is considerable interdependency between these factors. Any benefits we calculate should therefore not necessarily be interpreted in isolation. In particular, we note that mental and physical health may reinforce each other, in that improved physical health can improve mental health, and vice versa. Similarly, improvements in mental health and work productivity can lead to further improvements in the other categories.

There are two other channels that were considered but excluded due to insufficient quantitative information being available: the link between short breaks and parent couple relationships[9] and the link to in-work productivity. These are discussed further in Annex B.

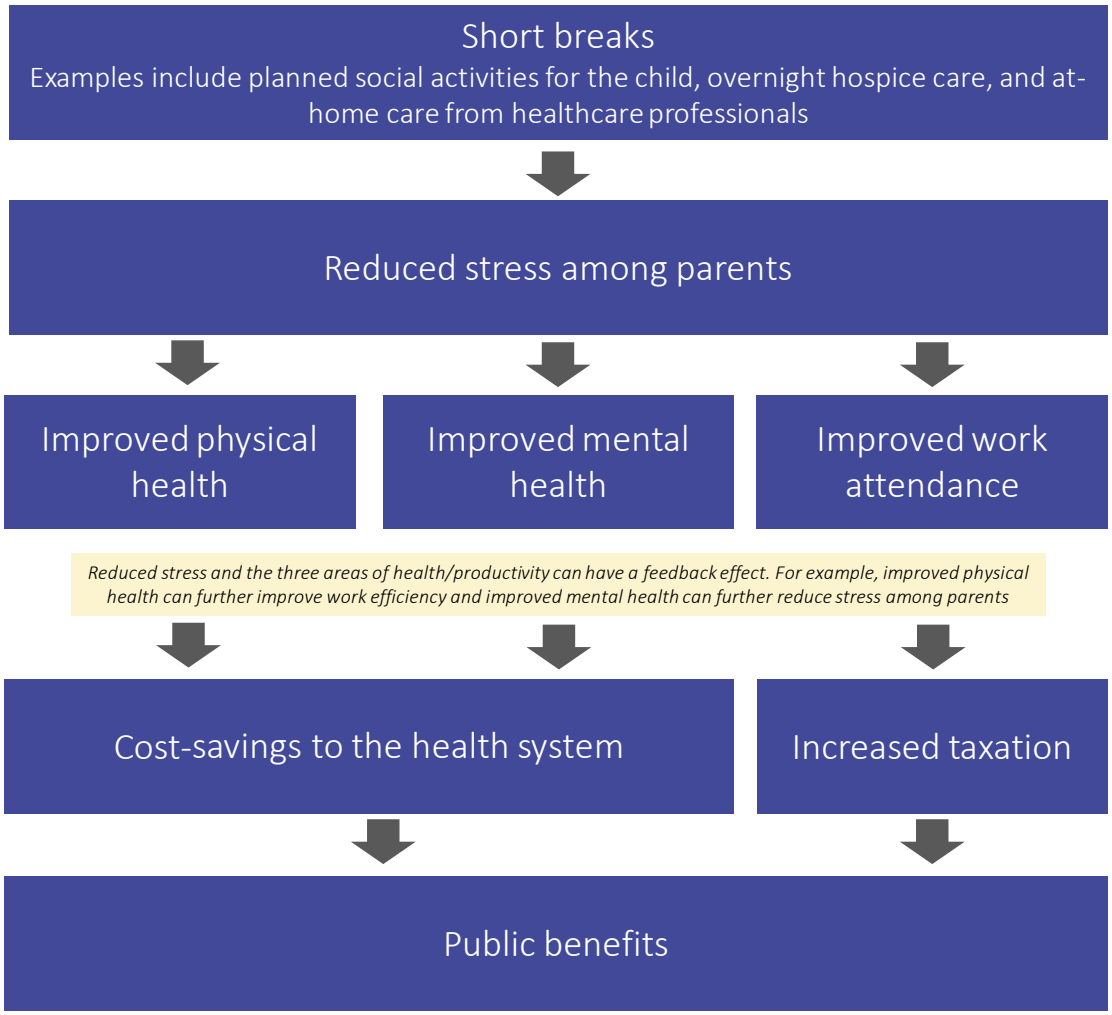
We lay out our methodology of quantifying the positive impact of short breaks through each channel:

- Parents of children with life-limiting or life-threatening conditions are under very high levels of stress;
- Short breaks are provided to the carer parents, which has a positive impact on their stress levels;
- Reduction in stress levels has a positive impact in the parents' lives through (at a minimum) the three channels mentioned above, namely physical and mental health and work attendance.
- For each of these channels, based on academic literature, we identify one relevant metric that captures this positive impact of stress on the particular channel. In particular (i) reduction of GP appointments for improved physical health; (ii) reduction of public expenditure on mental health per person for improved mental health, and; (iii) reduction of days of sickness absence.
- Lastly, we quantify the impact that an improvement in each indicator has on public spending. The public benefit of short-breaks is the sum of the cost-savings to the healthcare system and increased tax revenue.

Figure 1, below, summarises our approach:

[9] As part of this work we reviewed research commissioned by Julia's House and undertaken by Bournemouth University that did look at the impact on parental relationships of short breaks provided by children's hospices. Whilst a useful source – with some quantitative findings highlighting the positive impact of short breaks – we were unable to use the findings in our underlying assumptions

Figure 1. **Approach to quantifying public benefits from providing short breaks to parents**



Source: Compass Lexecon analysis

2.2 Approach in detail

In this section we review the approach taken for each of the key channels in more detail. We start by reviewing the link between short breaks for parent carers and levels of stress.

Relationship between short break and reduced stress

Short breaks have a direct impact on reducing parental stress. A study by Mullins et al. suggests that both short (three-to seven-day) and long (30-day) breaks reduce stress levels of parents of children with developmental disabilities[10]. A review of existing studies on parental stress in families with developmentally disabled children draws a similar conclusion showing that respite care is associated with significant reductions in parental stress in the short-term[11].

[10] Mullins, L. L., Aniol, K., Boyd, M. L., Page, M. C., & Chaney, J. M. (2002). The influence of respite care on psychological distress in parents of children with developmental disabilities: A longitudinal study. *Children's Services: Social Policy, Research, and Practice*, *5*(2), 123-138.

[11] Chan, J. B., & Sigafoos, J. (2001, October). Does respite care reduce parental stress in families with developmentally disabled children?. In *Child and Youth Care Forum* (Vol. 30, No. 5, pp. 253-263).

Finally, Cowen and Reed (2002) found significant effects of respite care on stress as measured by the Parenting Stress Index (PSI) [12].

While the specific needs of children with life-limiting or life-threatening conditions may differ from children with developmental disabilities, parents of children requiring palliative care are under similar stress conditions and could find relief through short breaks.

For our baseline scenario, we draw on the paper by Cowen and Reed (2002) to estimate that the proportion of parents experiencing highest levels of stress declined from 73.3% to 61.6% - a reduction of 11.7 % pts[13]. For comparison, based on a study by Harper et al. (2013), we estimate a 33% reduction in self-reported stress levels following respite care for parents of children with autism spectrum disorders[14].

Benefits from improved physical health of parents

We assess the impact of short breaks on physical health via their impact on reducing parental stress. In other words, we expect that short breaks reduce parental stress, and we would expect reduced parental stress in turn to improve physical health.

Stress is recognized as a contributor to increased risks of negative health outcomes such as cardiovascular diseases, metabolic diseases, and immunological problems[15]. By reducing stress, the risks of arriving at these negative health outcomes are reduced. Stress is also associated with risky health behaviours such as poor diet and substance abuse[16]. By reducing stress, parents benefit from healthier behaviours such as improved diet and lowered risks of substance abuse.

Compared to the general population, carer parents are particularly exposed to stress, and thus stand to gain more from the reprieve afforded by short breaks. In addition to the stress experienced by the general population, these parents also experience the following:

- Parental stress: Parents, regardless of whether their children have specific needs, experience stress related to child development, education, social expectations and conflicting demands between work and family.

[12] The Parenting Stress Index is a self-reported measure of the magnitude of stress arising as a result of parent-child interactions, measured based on the Parenting Stress Inventory. See Cowen, P. S., & Reed, D. A. (2002). Effects of respite care for children with developmental disabilities: Evaluation of an intervention for at risk families. Public Health Nursing, 19(4), 272-283.

[13] We assume that stress scores are normally distributed. Based on a pre-treatment mean of 289.6 and standard deviation of 47.5, and a post-treatment mean of 275.1 and standard deviation of 51.1, we estimate the change in the proportion of parents scoring above 260, the threshold considered by the authors to constitute high stress. Cowen, P. S., & Reed, D. A. (2002). Effects of respite care for children with developmental disabilities: Evaluation of an intervention for at risk families. *Public Health Nursing*, *19*(4), 272-283.

[14] Harper, A., Dyches, T. T., Harper, J., Roper, S. O., & South, M. (2013). Respite care, marital quality, and stress in parents of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *43*(11), 2604-2616. According to the study, the women subjects have a stress score of 107.09 before the treatment (men: 108.98). They then received 6.59 hours of respite care on average (men: 6.32), and saw a decrease of 5 points per hour of respite care received (men: 6), which is equivalent to a 4.67% (men: 5.51%) decrease in stress scores. When scaled up by the average number of respite care received, this becomes 30.77% (men: 34.80%). The average for women and men is therefore 32.78%.

[15] Steptoe, A., & Kivimäki, M. (2013). Stress and Cardiovascular Disease: An Update on Current Knowledge. *Annual Review of Public Health*, 34, 337-354. Keys, A., Fidanza, F., Karvonen, M. J., Kimura, N., & Taylor, H. L. (1972). Indices of relative weight and obesity. *Journal of chronic diseases*, *25*(6-7), 329-343. O'Leary, A. (1990). Stress, emotion, and human immune function. *Psychological bulletin*, *108*(3), 363.

[16] Among others, see Yau, Y. H. C., & Potenza, M. N. (2013). Stress and Eating Behaviors. *Minerva Endocrinol*, *38*(3), 255-267; Sinha, R. (2008). Chronic Stress, Drug Use, and Vulnerability to Addiction. *Annals of the New York Academy of Sciences*, 1141, 105-130; and Wand, G. (2008). The Influence of Stress on the Transition From Drug Use to Addiction. *Alcohol Research & Health*, *31*(2), 119-136.

- Stress unique to parents of children requiring palliative care: In order to address the needs of their children, the carer parents experience stress due to the increased demands on time, finances and mental resources[17].

For the scope of this study, we focus on a single indicator of physical health that is easily quantified: the number of visits to the GP. This is by no means a comprehensive accounting of the physical health factors that are affected by short breaks or stress, but it serves to illustrate the cascading impact of how short breaks decrease parental stress, leading to improved physical health and benefits to the public sector.

We use the number of avoided visits to the GP to measure the impact of improved physical health among carer parents. We then calculate the public benefits associated with the avoided visits to the GP. Full details of our approach are available in Annex A but it can be summarised as follows:

- We draw on evidence from Denmark to estimate that those who are in the highest stress category typically see their GPs 8% more frequently than those in the next category down[18].
- We estimate that a highly stressed person is likely to visit the GP around 7.4 times per year on average. Therefore an 8% reduction from reducing stress levels is the equivalent of an average reduction of 0.6 GP visits per year[19].
- A single GP visit is estimated to cost £70; therefore, the taxpayer saving generated by reducing the stress levels of a parent from the highest category to the next category down is, on average, likely to be around £41 per parent per year
- We estimated above that 11.7% pts. fewer parents would experience the highest stress levels as a result of the provision of short breaks. Therefore, the average taxpayer savings due to reduced demand on the NHS is likely to be around £4.77 per parent.
- If we assume an average of 1.6 parents per family, then this equates to £7.83 per family of a child who needs palliative care[20].

This estimate appears to be very conservative compared to results of a similar study that estimated that without additional support parents of disabled children would make four additional visits to a GP each year, generating potential savings of £286 per disabled child[21].

Benefits from improved mental health of parents

Providing palliative care for children can be very demanding on parents. Aside from daily caring activities, parents often experience the burden of *"decreased social and cultural activities, disruption in employment, financial strain and feelings of guilt and isolation"* [22]. As a result, parents of children with disabilities report mental health problems more frequently than parents of healthy children[23].

---

[17] Vitaliano, P. P., Zhang, J., & Scanlan, J. M. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological bulletin*, *129*(6), 946.

[18] Prior, A., Vestergaard, M., Larsen, K. K., & Fenger-Grøn, M. (2018). Association between perceived stress, multimorbidity and primary care health services: a Danish population-based cohort study. *BMJ Open, 8*(2), e018323.

[19] Based on NHS Digital (2018) figures for total number of GP appointments and ONS (2019) population figures, adjusted for the incidence of daytime consultations amongst groups with different stress levels in Prior et al. (2018).

[20] This is based on the proportion of single-parent and two-parent households for disabled children. In the ansence of a more accurate figure we assume this is the same as for parents of children in palliative care.

[21] See Copps, J., & Heady, L. (2007). What price an ordinary life?: The financial costs and benefits of supporting disabled children and their families. *New Philanthropy Capital*, p. 15. The Copps and Heady (2007) estimate provides no evidence to support the increase in GP visits and effectively assumes that these costs could be entirely alleviated through additional interventions and support.

[22] Wallander, J. L., Pitt, L. C., & Mellins, C. A. (1990). Child functional independence and maternal psychosocial stress as risk factors threatening adaptation in mothers of physically or sensorially handicapped children. *Journal of Consulting and Clinical Psychology*, *58*(6), 818.

[23] Byrne, E. A., & Cunningham, C. C. (1985). The effects of mentally handicapped children on families–a conceptual review. *Journal of Child Psychology and Psychiatry*, *26*(6), 847-864.

We use a top-down approach to compute the public benefits from improved mental health. We first estimate the average public expenditure on mental health per person. We then calculate the impact of short breaks on the public expenditure on mental health. Full details of our approach are available in Annex A but it can be summarised as follows:

- We draw on the evidence from Denmark to estimate that those in the highest stress category typically use 49% more mental health expenditure than the next category down[24].
- Drawing on a report by the OECD, we estimate that the average mental health spending for a highly stressed individual is £1,875 per year[25].
- Therefore the benefit from helping a single parent out of the most stressed group is likely to be around £921 per year.
- As above, we assume that 11.7% fewer parents would experience the highest stress levels as a result of the provision of short breaks. Therefore, the average taxpayer savings due to reduced demand on the NHS is likely to be around £108 per parent.
- If we assume an average of 1.6 parents per family, then this equates to £177 per family of a child in palliative care.

Benefits from improved work attendance

There is well-documented evidence on the link between stress levels and work absence. A study by Verhaeghe et al. points to increased absenteeism among stressed workers[26]. Other studies attribute the impact of stress on absenteeism to worsened health[27].

Based on the Labour Force Survey, the Health and Safety Executive of the UK Government shows that an average of 21.2 working days were lost to stress, depression or anxiety among those reporting work-related sickness in 2017/2018[28]. It is important to note this does not represent an average across the total workforce population, only those reporting work-related sickness. This is the highest number of out of the health problems analysed, including injuries, musculoskeletal disorders, and other sicknesses.

We use the number of avoided sick days to measure the impact of reduced absenteeism due to short breaks. We then calculate the public benefits associated with the avoided sick days. Full details of our approach are available in Annex A, but it can be summarised as follows:

- We draw on literature suggesting that those who are "often/always" stressed tend to incur 12% more days of sick leave than those who are "sometimes" stressed[29].
- The average number of sick days lost due to stress for a full-time worker is estimated to be 21.2 days[30].
- Therefore, helping a single parent who is working full-time out of the most stressed group is likely to reduce sickness absence by 2.6 days per year[31].

---

[24] Prior et al. (2019)

[25] Costs are taken from OECD (2018). Health at a glance: Europe 2018, pp28-29: https://read.oecd-ilibrary.org/social-issues-migration-health/health-at-a-glance-europe-2018_health_glance_eur-2018-en#page19. Population figures are taken from ONS (2019). The mean spending per adult is adjusted to reflect the Incidence Ratios for antidepressant prescriptions in Prior et al. (2018).

[26] Verhaeghe, R., Mak, R., Maele, G. V., Kornitzer, M., & Backer, G. D. (2003). Job stress among middle-aged health care workers and its relation to sickness absence. *Stress and Health: Journal of the International Society for the Investigation of Stress*, *19*(5), 265-274.

[27] Joensuu, M., & Lindström, K. (2003). Sickness absence and stress factors at work. *Helsinki: Finnish Institute of Occupational Health*.

[28] Health and Safety Executive (2017/2018). Working Days Lost in Britain. Retrieved from <http://www.hse.gov.uk/statistics/dayslost.htm> on November 4 2019.

[29] Based on the reduction in hazard ratios reported in Thorsen, S. V., Pedersen, J., Flyvholm, M., Kristiansen, J., Rugulies, R., & Bültmann, U. (2019). Perceived stress and sickness absence: a prospective study of 17,795 employees in Denmark. *International Archives of Occupational and Environmental Health*, *92*(6), 821–828

[30] Labour Force Survey 2017/18

[31] 12% * 21.2 days = 2.6 days

- This is estimated to generate around £687 of added value for the economy, of which £130 could be realised by government based on the marginal corporate tax rate[32].
- As above, we assume that 11.7% fewer parents would experience the highest stress levels as a result of the provision of short breaks, therefore the average increase in tax revenue for the government from this reduction in sickness absence is likely to be £15.29 per year for each parent who is working full-time.
- We assume that, on average, there is 0.8 parent working full-time per child in palliative care, and therefore the average benefit per family of a child in palliative care is £12.72 per year.

To assess the overall taxpayer benefits we multiply the benefits per family by 24,929 – the estimated number of children who need palliative care in the UK[33].

Summary of benefits

Figure 2 summarises the taxpayer benefits identified.

Figure 2. **Summary of benefits from short breaks for parent carers**

Channel	Potential benefit from fully changing stress levels of one parent	Average benefit per parent from a short break	Average benefit per family from a short break
Improved physical health	£40.71	£4.77	£7.83
Improved mental health	£921.39	£108.00	£177.12
Improved work attendance	£130.46	£15.29	£12.72[34]

Source: Compass Lexecon analysis

[32] Gross Value Added (GVA) of the UK divided by the number of hours worked in the UK in 2018 (£35.37/hour); this is then multiplied by the average number of hours worked per day by full-time employees (7.42 hours) to obtain the average productivity per day of a full-time employee (£262.44/day). We then apply the marginal Corporation Tax Rate of 19% to estimate taxpayer benefits.

[33] The number of children in palliative care in the UK is calculated as the prevalence rate multiplied by the population of children from the Office of National Statistics ("ONS"). The prevalence rate is 16 per 10,000 and is provided by Craft, A., & Killen, S. (2007). Palliative care services for children and young people in England. Secretary of State for Health, p.21. Retrieved from: https://www.nsf.no/Content/662668/PALLIATIVE_CARE_SERVICES_FOR_CHILDREN.pdf on 25 June 2019.f

[34] The benefits from improved work attendance are smaller per family compared to the benefit per parent because we assume, on average, there are 0.8 parents working full-time per child in palliative care.

Box 1: Applying benefit estimates to individual case studies

The figures outlined in Section 2.2 can be used to help estimate the cost of specific case studies. This can be used to provide illustrative examples tailored to the specific characteristics of particular family rather than relying on averages which can start to feel very abstract. We provide a hypothetical example below informed by discussions with service providers.

Case-study example: Emma, Ian, Emily and Hugo

Emma and her husband Ian live in Somerset with their two children, Emily, 8, and Hugo, 6. Hugo has Congestive Heart Failure (CHF), resulting in constant feelings of tiredness and lethargy. Emma works part-time as a nurse, while Ian works full-time as a personal assistant.

Hugo requires extensive care and support, which puts significant strain on Emma and Ian's marriage. They can no longer spend weekends doing their usual leisure activities such as walking, cycling and exercising. Evenings spent together are usually tense and stressful. The couple is limited on how much they can work without putting Hugo's health at risk, even as demand on their finances increase due to Hugo's care.

We know that prior to benefiting from short breaks Emma and Ian had attended 15 GP appointments the previous year and both had utilised mental health services provided by the NHS. One of the two parents works full-time and took 25 sick days in the last year. We do not have exact follow-up data but both parents report feeling significantly less stressed as a result of the short breaks provided. As such we would expect:

Costs of GP visits: The number of GP visits to reduce by 8% (1.2 appointments). This will save the NHS around £82 (1.2*£70.30).

Costs of mental health services: We may not have exact figures for their usage of mental health services but we know that if they were feeling highly stressed prior to the intervention and are feeling significantly less stressed after benefiting from short-breaks then it might save £921 for each of them, equivalent to £1,842 overall.

Tax savings from reduced absenteeism: We would expect the number of sick days to reduce by around 12% (3 days). This is worth around £809.72 in Value Added to the economy. Which at a Corporate Tax Rate of 19% is worth around £150 in increased tax.

Overall, this hypothetical case study could have saved taxpayers more than £2000.

2.3 Key assumptions

There are several key assumptions that underly our analysis:

- The key study used to establish the link between provision of short breaks and a reduction in stress for carers is based on evidence from the USA. We are assuming that the impacts will be similar for the UK. Furthermore, the study used a before-after comparison to assess the impacts of short breaks on care and made no comparison to a control group. This means that we cannot be certain of the causal impact of short breaks on the reduction in stress. To reflect this, we explore some alternative assumptions as part of our sensitivity analysis in Section 3.2.
- We have been unable to quantify the impact of several channels through which short breaks could influence taxpayer benefits such as the impact on in-work productivity, the impact on parent couples relationships and the impact on parental earnings. We include a scenario in our sensitivity analysis looking at the potential impact of in-work productivity in Section 3.2.
- Throughout this report we use evidence based on carers of disabled children as a proxy for carers of children with life-threatening or life-limiting diseases. Existing literature on the quantitative impact of respite care on carers for children with life-threatening conditions is sparse, partly due to the sensitive nature of the research topic and ethical considerations and small sample sizes. In some instances, we expand the scope of analysis to also look at carers for children with other types of disabilities. While there may be differences in the urgency and complexity of care, expanding the scope of analysis allows us to build on the more extensive research that have been carried out by researchers of carers for children with disabilities. In some instances, we also refer to the literature on carers in general: carers for the elderly or for adults with terminal diseases.

- We abstract away from the different types of carers – parents, grandparents, siblings, neighbours, etc. Without data on the distribution of types of carer, we follow similar studies by focusing on parents as the predominant type of carer.
- We assume that the effect of short breaks remains constant over time. In other words, we do not model sustained impact (e.g. a parent may use the time gained from a short break to find a better job, which causes a prolonged and wide-ranging impact on her life) and we do not model diminishing impact (e.g. short breaks may have a large impact on a parent's health the first year that the service is provided but a smaller impact in subsequent years). One study finds that the impact of short breaks over time depends on the intensity/frequency of the intervention (i.e. the number of hours of short breaks received) [35].
- We rely heavily on evidence from Denmark to establish the impacts of stress on the use of health services and the amount of sickness absence. We are assuming that these impacts will be similar in the UK.

Overall, we believe that the estimates calculated under this methodology are conservative and should be considered as a lower-bound for the positive impact of short breaks on public spending.

[35] Singer, G. H., Irvin, L. K., Irvine, B., Hawkins, N., & Cooley, E. (1989). Evaluation of community-based support services for families of persons with developmental disabilities. *Journal of the Association for Persons with Severe Handicaps*, *14*(4), 312-323.

3. Results of our analysis

In this section we take the benefits per family identified in Section 3.2 and apply these to the total number of children in palliative care in the UK to estimate the potential taxpayer benefits from providing short breaks for all children in palliative care. Section 4.1 provides a summary of our estimate of total taxpayer benefits and section 4.2 explores the impact of varying some of the key assumptions behind our analysis.

3.1 Total taxpayer benefits

We find that £4.9 million of taxpayer benefit could be generated if all families with children in palliative care were able to access short breaks. The majority (90%) of this benefit could be generated from reduced spending on mental health services; increased taxation due to improved work attendance accounts for 6% of the benefits; and reduced demand for GP appointments accounts for 4% of the benefits. Again, it is important to note the overlap/interdependencies between these channels. This is summarised in Figure 3.

Figure 3. **Total taxpayer benefits from providing short breaks for parent carers**

Channel	Average benefit per family from a short breaks	Total potential benefit from all families of children in palliative care
Improved physical health	£8	£0.2 million
Improved mental health	£177	£4.4 million
Improved work attendance	£13	£0.3 million
Total benefit	**£198**	**£4.9 million**

Source: Compass Lexecon analysis

3.2 Sensitivity Analysis

In this section we explore the sensitivity of our analysis to two key assumption:

- Sensitivity 1: The link between short breaks and a reduction in stress.
- Sensitivity 2: The inclusion of in-work productivity benefits.

Sensitivity 1: The link between short breaks and a reduction in stress

Our baseline scenario assumes that the change in stress levels caused by short breaks is similar for parents with children in palliative care as it is for parents of severely disabled children. In addition, it assumes that the findings from a study in the USA are broadly applicable in the UK context. It is not possible to say whether we would expect the impact of short breaks to be more or less for UK parents with children in palliative care, so we explore both higher impact and lower impact scenario as follows:

- **Higher impact scenario:** We assume that short breaks reduce the proportion of parents with "high stress levels" by 33%, in line with the findings of Harper et al (2013).
- **Lower impact scenario:** We assume that short breaks reduce the proportion of parents with "high stress levels" by 9%, the equivalent of 75% of the improvement used in our central case.

Table 4 summarises the findings of these sensitivity tests. The total benefit from providing short breaks for parents caring for children in palliative care are estimated to be in the range of £3.7 million and £13.8 million depending on the assumption of the impact of short breaks on stress levels. This demonstrates a plausible range for the total benefit from providing short breaks.

Figure 4. **Total benefit for alternative relationships between short breaks and stress**

	Lower impact scenario	Baseline scenario	Higher impact scenarios
Total benefit	**£3.7 million**	**£4.9 million**	**£13.8 million**

Source: Compass Lexecon analysis

Sensitivity 2: The link between short breaks and in-work productivity

As discussed in Annex B, there is insufficient evidence to confidently quantify the impact of short-breaks on in-work productivity or "presenteeism". However, we draw on a review by the Centre for Mental Health that suggests the scale of presenteeism benefits could be around two times higher than the scale of absenteeism benefits for general mental health conditions. If we apply this to the impact of stress then we find that it could increase total benefit by around £0.3 million, as summarised by Figure 5.

Figure 5. **Total benefit including the impact of in-work productivity**

	Including in-work productivity impacts	Baseline scenario
Total benefit	**£5.2 million**	**£4.9 million**

Source: Compass Lexecon analysis

4. Conclusion

Our study has provided an initial estimate of the potential taxpayer benefits from providing all parents with children in palliative care with short breaks. We have drawn on literature linking short breaks for carers to reduced levels of stress and examined the potential impact of this on expenditure for physical health and mental health as well as the potential impact on tax revenue as a result of increased productivity of parents at work.

Our key findings are as follows:

- We find evidence that 11.7% of parents of children in palliative care would experience a significant reduction in stress as a result of providing them with short breaks.
- For every parent who experiences a reduction in stress we would expect this to reduce expenditure on GP visits by £41 and mental health expenditure by £921.
- For every parent who experiences a reduction in stress we would expect this to reduce the number of days taken off work by around 2-3 days per year.
- The total potential benefits to taxpayers from providing short breaks to all parents of children in palliative care could be in the region of c£5 million per year, based on the assumption that there to be around 25,000 children who need palliative care in the UK, with parents most commonly acting as their primary carer.

Implications

Our analysis suggests that the benefits from providing short breaks to carer parents extend beyond the parents themselves. Short breaks generate public benefits through cost-savings to the healthcare system and increased tax revenue. Although an examination of the costs of providing short breaks to all parents of children in palliative care is outside the scope of this report, we hope that our evidence can further support the case for helping those parents who are dealing with such demanding and challenging situations.

However, we recognise that this analysis is by no means a comprehensive accounting of the factors that are affected by the provision of short breaks and that there are limitations to the evidence we have been able to use. Future assessments of the potential economic impacts of short breaks for parents providing palliative care would be strengthened by:

- Developing evidence of the impact of short breaks on clinical measures of stress specifically for parents providing palliative care in the UK. At present our study has relied on studies assessing the impact of short breaks on stress for parents caring for severely disabled children in the USA and assumed that the impacts will be similar.
- Assessing the impact of this care directly on the demand for health services such as appointments with GPs and mental health support.
- Building evidence on other, wider impacts so that they can be included, such as the impact on in-work productivity, parental relationships, wellbeing, leisure or discretionary spending.

Annex A – Detailed Methodology

This annex provides additional details of the calculations made to estimate the potential taxpayer benefits from providing short breaks for parents with children in palliative care.

Benefits from improved physical health of parents

The number of avoided visits to the GP per parent receiving short breaks is calculated as follows:

$$Avoided\ visits = Impact_{Short\ breaks} * Impact_{Stress} * \#\ visits$$

where $Impact_{Short\ breaks}$ is the percentage impact of short breaks on reducing stress; $Impact_{Stress}$ is the percentage impact of stress reduction on reducing the number of GP visits; and $\#\ visits$ is the number of visits to the GP for a highly stressed person in the UK. We explain our methodology for determining each variable in detail below.

$Impact_{Short\ breaks}$ is calculated using the results from a paper by Cowen and Reed (2002). The two authors find significant effects of respite care on stress, where stress is measured by the Parenting Stress Index (PSI) [36]. Using the mean and standard deviations provided in the paper, we calculate that 73.3% of parents of children with disabilities experienced high levels of parenting stress before the short break intervention[37]. After the intervention, this figure decreased to 61.6%[38].This suggests an 11.7% pt decline in the number of highly stressed parents as a result of the short breaks[39]. For comparison, based on a study by Harper et al. (2013), we estimate a 33% reduction in self-reported stress levels following respite care for parents of children with autism spectrum disorders[40].

$Impact_{Stress}$ is calculated using the results from a paper by Prior et al. (2018) [41]. The researchers quantify *"the association between perceived stress and primary care services"*, where perceived stress is defined on the Perceived Stress Scale (PSS) and the primary care services examined include GP consultations. We estimate that somebody will require 8% fewer GP appointments if they have a normal PSS score compared to those in the highest stress category[42]. Based on this we assume that demand for GP services declines by 8% as a result of an individual moving out of the most stressed category.

---

[36] The Parenting Stress Index is a self-reported measure of the magnitude of stress arising as a result of parent-child interactions, measured based on the Parenting Stress Inventory. See Cowen, P. S., & Reed, D. A. (2002). Effects of respite care for children with developmental disabilities: Evaluation of an intervention for at risk families. *Public Health Nursing*, *19*(4), 272-283.

[37] Mean of 289.6 and standard deviation of 47.5, a high score of stress relates to a score above 260 from Cowen, P. S., & Reed, D. A. (2002). Effects of respite care for children with developmental disabilities: Evaluation of an intervention for at risk families. *Public Health Nursing*, *19*(4), 272-283.

[38] Mean of 275.1 and standard deviation of 51.1, a high score of stress relates to a score above 260 from Cowen, P. S., & Reed, D. A. (2002). Effects of respite care for children with developmental disabilities: Evaluation of an intervention for at risk families. *Public Health Nursing*, *19*(4), 272-283.

[39] (61.62% – 73.34%) / 61.62% = 15.98%. In Appendix B, we present a sensitivity showing the impact of assuming a more moderate decline (three-quarters of 15.98%) or a more aggressive decline (one and a half times of 15.98%) in stress scores.

[40] Harper, A., Dyches, T. T., Harper, J., Roper, S. O., & South, M. (2013). Respite care, marital quality, and stress in parents of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *43*(11), 2604-2616. See footnote 14.

[41] Prior, A., Vestergaard, M., Larsen, K. K., & Fenger-Grøn, M. (2018). Association between perceived stress, multimorbidity and primary care health services: a Danish population-based cohort study. *BMJ Open, 8*(2), e018323.

[42] The frequency of GP visits for a given stress level is given in terms of an Adjusted Incidence Rate Ratio (IRR), which measures the relative frequency of a primary care service relative to a baseline. "Adjusted" refer to the adjustments the authors made to account for lifestyle and socioeconomic factors. A high PSS score is defined as a score in the top quintile of the PSS distribution, based on the paper's description that the *"fifth quintile values are often considered abnormal."* A normal PSS score is conservatively assumed to be a score in the fourth quintile of the PSS distribution. This assumption is conservative because the difference in stress levels compared to the top quintile would be even larger if the third or second quintile is used.

$\#\ visits$ is calculated using NHS data. Based on NHS analysis, 307 million GP appointments took place in England between 1 November 2017 and 31 October 2018[43]. The population of England in mid-2018 was 55,977,000 individuals[44]. Hence, we estimate that the average person in England visits the GP 5.5 times a year. Prior et al. (2018) suggest that those in the most stressed category use around 35% more daytime consultations compare to the mean. Therefore, we assume the most stress cohort attend around 7.4 appointments on average per year.

Using the impact of short breaks on stress, the impact of stress on visits, and the estimated number of visits to the GP calculated above, the average number of avoided visits per parent is 0.07[45].

The public benefits associated with the avoided visits to the GP is calculated as follows:

$$Cost - savings = Avoided\ visits * Costs\ per\ visit$$

where $Avoided\ visits$ is 0.07 and $Costs\ per\ visit$ is the cost of an average visit to the GP. The total cost of a GP appointment with prescription is £70.30 according to an analysis on the unit costs of healthcare at the NHS in 2018[46]. This estimate includes renumeration for the medical staff, the cost of providing qualifications for doctors, as well as cost of any prescribed medicine.

This provides a saving per parent from reduced demand for GP appointments of £4.77 per year.

Benefits from improved mental health of parents

We use a top-down approach to compute the public benefits from improved mental health. We first estimate the average public expenditure on mental health per person. We then calculate the impact of short breaks on the public expenditure on mental health as follows:

$$Savings = Impact_{Short\ breaks} * Impact_{Stress} * Spending$$

where $Impact_{Short\ breaks}$ the percentage impact of short breaks on reducing stress; $Impact_{Stress}$ is the percentage impact of stress reduction on reducing the public expenditure on mental health; and $Spending$ is the expected public expenditure on mental health for a highly stressed person in the UK. We explain our methodology for determining each variable in detail below.

$Impact_{Short\ breaks}$ is the same impact on stress (11.7% pts) as previously calculated.

$Impact_{Stress}$ is calculated using the results from a paper by Prior et al. (2018) using the same methodology as previously. Since the study does not directly measure mental health spending, we select the mental health-related service that is most often used and hence most representative: antidepressants prescriptions. We estimate the impact of stress on mental health spending by comparing the frequency of antidepressants prescriptions for someone with a high PSS score against the frequency of antidepressants prescriptions for someone with a normal PSS score[47]. On this basis we assume that the demand for mental health services falls by 49% as an individual moves out of the most stressed category.

---

[43] NHS Digital (2018). Appointments in general Practice, October 2018 [PAS]. Published 6 Dec 2018. Retrieved from <https://digital.nhs.uk/data-and-information/publications/statistical/appointments-in-general-practice/oct-2018> on July 15 2019.

[44] Office for National Statistics (2019). Population estimates for the UK, England and Wales, Scotland and Northern Ireland: mid-2018. Retrieved from <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/bulletins/annualmidyearpopulationestimates/mid2018> on June 25 2019.

[45] Avoided visits = Impact of short breaks on stress * Impact of stress on visits * Average number of visits = 11.7% * 7.81% * 7.4 = 0.06 visits.

[46] The appointment assumes a consultation lasting 9.22 minutes, including direct care staff costs and qualification costs. The prescription assumes the net ingredient cost. See Curtis, L. A., & Burns, A. (2018). Unit Costs of Health and Social Care 2018. Project report. University of Kent. Retrieved from < https://kar.kent.ac.uk/70995/> on July 15 2019, pp. 126–128.

[47] See footnote 42 for discussion on high and normal PSS scores.

$Spending$ is calculated by dividing the total public expenditure on mental health by the UK population. According to a study published by the OECD, the total direct costs of mental health problems to the UK public sector was £42.8 billion in 2015[48]. Based on a population of 65 million[49], we estimate that the (mean) average spending in mental health problems per person to be £658 in 2015 in the UK[50]. Evidence from Prior et al. (2018) suggests that those in the most stressed categories tend to consume 185% more mental health services than the mean. Therefore, we assume that average expenditure on mental health services for somebody in the most stressed category is likely to be in the region of £1,900 per year.

The public benefits per parent from improved mental health provided with short breaks is therefore £108[51]. This is estimated to be an average saving of £177 per family.

Benefits from improved work attendance

The impact of short breaks on absenteeism is calculated as follows:

$$Avoided\ sick\ days\ = Impact_{Short\ breaks} * Impact_{Stress} * \#\ sick\ days$$

where $Impact_{Short\ breaks}$ is the same impact on stress (11.7% pts) as previously calculated; $Impact_{Stress}$ is the percentage impact of stress on productivity, as explained below; and $\#\ sick\ days$ is the average number of working days lost to stress (21.2 days), as shown previously.

$Impact_{Stress}$ is calculated using the results from a paper by Thorsen et al. (2019) [52]. The researchers examined *"the prospective association between perceived stress and sickness absence"*, where perceived stress is classified as one of three levels (often/always, sometimes, and seldom/never) and sickness absence is reported as the relative likelihood (hazard ratio) compared to a baseline of an individual taking sick leave.

The impact of stress on productivity is hence calculated as the reduction observed in the hazard ratio of those in the often/always stressed category compared to the hazard ratio of those in the sometimes-stressed category. The results are separated by sex in the study, which revealed a difference in magnitude but similarity in qualitative impact. In our analysis, we use the average impact of stress on productivity between women and men. Therefore, we assume that on average the most stressed people take 12% more sick days than less stressed people.

$Avoided\ sick\ days$ is therefore 0.3 days[53].

We note that the average number of sick days used above describe the behaviour of those who are highly stressed.

---

[48] Direct costs include "both those borne by health care systems to provide treatments to mental health problems and additional social security spending, including paid sick leave benefits, disability benefits and unemployment insurance benefits", according to the OECD. Of the cited figure, the annual direct costs on healthcare systems that would be borne by the NHS is £26.4 billion. Figures presented are converted from € to £ using the 2015 average exchange rate of 1.38 €/£. Health at a Glance: Europe 2018. Retrieved from < https://read.oecd-ilibrary.org/social-issues-migration-health/health-at-a-glance-europe-2018_health_glance_eur-2018-en#page19> on October 7 2019: pp. 28-29.

[49] Office for National Statistics (2018). Population estimates for the UK, England and Wales, Scotland and Northern Ireland: mid-2015. Retrieved from < https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/bulletins/annualmidyearpopulationestimates/mid2015> on October 7 2019.

[50] We used the average exchange rate for 2015 from the European Central Bank: 1.38 €/£.

[51] Public benefits = Impact of short-breaks on stress * Impact of stress on mental health spending * Average public expenditure on mental health per person = 11.7% * 49% * £1,900 = £101.

[52] Thorsen, S. V., Pedersen, J., Flyvholm, M., Kristiansen, J., Rugulies, R., & Bültmann, U. (2019). Perceived stress and sickness absence: a prospective study of 17,795 employees in Denmark. *International Archives of Occupational and Environmental Health*, *92*(6), 821–828.

[53] Avoided sick days = Impact of short breaks on stress * Impact of stress on productivity * Average number of sick days = 11.7% * 12% * 21.2 = 0.3 days.

The public benefits associated with reduced absenteeism is calculated as follows:

$$Benefits = Avoided\ sick\ days * Number\ Employed * Average\ productivity * Tax\ rate$$

where:

$Avoided\ sick\ days$ is 0.3 days (see above);

$Number\ employed$ is the average number of employed parents per child with life-limiting or life-threatening diseases (0.83) [54];

$Average\ productivity$ is calculated as the total Gross Value Added (GVA) of the UK divided by the number of hours worked in the UK in 2018 (£35.37/hour); this is then multiplied by the average number of hours worked per day by full-time employees (7.42 hours) to obtain the average productivity per day of a full-time employee (£262.44/day); and

$Tax\ rate$ is the current UK corporate tax rate (19%)[55].We assume that increased productivity results in a proportional increase in a company's profits, and thus a proportional increase in the UK tax revenue.[56] We recognise that this relationship will not necessarily be linear, and/or that not all parent carers will be working in 'for profit' organisations.

The public benefit per child whose family is provided with short breaks from reduced absenteeism at work is therefore £12.7[57].

[54] This is based on a weighted proportion of the number of parents with disabled children in full-time and part-time employment taken from Working Families (2018). 2018 Off Balance – Parents of disabled children and paid work. Retrieved from <https://www.workingfamilies.org.uk/wp-content/uploads/2018/07/WF-2018-Off-Balance-pages-FINAL.pdf> on June 11 2019.

[55] UK Government (2019). Corporation Tax rates and reliefs. Retrieved from <https://www.gov.uk/corporation-tax-rates> on June 18 2019.

[56] Our model applies the corporate tax rate to calculate the public benefit resulting from increases the parents' productivity. There are, therefore, two implicit assumptions in this methodology:

a) The main assumption is that increased productivity is assumed to increase company profits proportionally. While this assumption is unlikely to be true in general, it is reasonable for marginal increases. In any case, even if some of the increased productivity is credited to wages (for example, as increased bonuses), the marginal increase in wages would likely correspond to an even higher tax rate than the overall corporate tax rate. This shows that we have taken a conservative approach to estimating the impact of short breaks on tax revenue.

b) This methodology abstracts from the fact that some parents may be self-employed or working for the public sector. Those who are self-employed have a different tax situation and contribute to the public benefit at a different rate, while those who are working for the public sector essentially would see their entire increase in productivity contributing to public benefits, hence making the use of corporate tax a very conservative assumption.

[57] Benefits = Avoided sick days * # highly stressed * Average productivity per hour * Average hours worked per day * Tax rate = 0.3 * 0.83 * £35.37 * 7.42 * 19% = £13.

Annex B – Impact of short breaks on parent couples relationships and in-work productivity

We reviewed the evidence linking short breaks for carers and improved parent couple relationships and in-work productivity. In both cases there is evidence available that suggests there is likely to be a relationship but there was insufficient evidence to quantify this link.

The link between short breaks and parent couple relationships

In this section, we highlight the impact of short breaks on the parent couple relationships of parents. We begin by discussing how short breaks improve parent couple relationships and then discuss the ways improved parent couple relationships can lead to public benefits.

The quality of parent couple relationships has spill-over effects on many aspects of society. The impact has been researched to some extent, however, most research on the subject focuses on qualitative assessments. As a result, the effect of short breaks on parent couple relationships cannot yet be reliably quantified. We therefore discuss at a high level the ways in which improved parent couple relationships can bring about public benefits without providing a quantification.

How short breaks improve parent couple relationships

Carer parents are at risk of having strained parent couple relationships, and short breaks can often improve the quality of those relationships. We explain each of these two points below.

Caring puts a strain on parent couple relationships and this is evident in the literature. Since taking care of a child with life-limiting or life-threatening diseases increases stress levels and pervades through many parts of everyday life, carer parents often experience a strain on their parent couples relationships[58]. Some of the mechanisms through which caring can affect parent couples relationships identified by Mitchell[59] (2017) include:

- social isolation;
- missing sleep and chronic fatigue;
- uncertainty and emotional impact of seeing rapid changes in their child's health;
- limited financial and employment opportunities; and
- the costs involved in caring, such as specialised dietary food, medicine, travel, medical equipment and home adaptations.

As a result of the strain due to caring, parents of children in palliative care can benefit immensely from short breaks. As discussed in Section 3, short breaks reduce the incidence of stress, which is a major contributor to a strained parent couples relationship. Furthermore, short breaks enable parents to spend time together pursuing joint activities and shift the focus from caring to addressing their own needs. Indeed, the provision of short breaks is designed to "support the integrity of the family unit" [60].

Several studies have confirmed the relationship between a reduction of parent couple distress and short breaks. Again, this is due to the effect short breaks have on stress levels. Harper et al. found a positive correlation between respite

[58] Harper, A., Dyches, T. T., Harper, J., Roper, S. O., & South, M. (2013). Respite care, parent couples quality, and stress in parents of children with autism spectrum disorders. *Journal of autism and developmental disorders*, *43*(11), 2604-2616.

[59] Mitchell, AJE. (2017). 'Can we fix it?' Understanding the impact of children's hospice short breaks on parental relationships of life-limited and life-threatened children and young people. Bournemouth University in association with Julia's House.

[60] Mullins, L. L., Aniol, K., Boyd, M. L., Page, M. C., & Chaney, J. M. (2002). The influence of respite care on psychological distress in parents of children with developmental disabilities: A longitudinal study. *Children's Services: Social Policy, Research, and Practice*, *5*(2), 123-138.

care and parent couple quality in families of children with autism spectrum disorder[61]. Norton et al. present similar conclusions for parents of children with Down syndrome[62].

The stress caused by the care of both children with autism spectrum disorder and children with Down syndrome is comparable to the one caused by the care of children with life-limiting or life-threatening conditions. As explained previously, while the care might vary in terms of urgency or complexity, the fundamental effect on the carer is similar.

Public benefits from improved parent couple relationships

Public benefits from improved parent couple relationships can arise in a variety of ways. To the extent that improved parent couple relationships can reduce divorces, tax credits and housing benefit to single parents will be reduced. To the extent that improved parent couple relationships improve general behaviour, public spending on the justice system and on monitoring behavioural problems will be reduced.

Research on the impact of parent couple relationships and divorce on social outcomes often focus on the impact on children. The risk of poverty for children living with a lone parent is twice as high as for children living with two parents and this has long term effects on school performance, employment and income[63].

In this paper, we do not put forward an estimate on the public benefits from improved parent couple relationships because we have not identified an adequate source for the social costs of impacted parent couple relationships. We do find support that such benefits exist and the policies taken by the government so far suggest that they could be significant; Mitchell (2017) states that "[k]*eeping families together is high on the government agenda in a bid to reduce the burden on social care and the state*".

The link between short-breaks and in-work productivity

Here we are referring to the phenomenon where a worker may be "present" for the same number of hours as another worker but is less productive due to the impact of stress.

There is an established literature on the potential costs of caring activities on productivity. A study by Giovanetti et al. found that the mental burden of caring for older adults with complex medical needs reduces productivity of caregivers by an average of 18.5%[64]. A related study by Mazanec finds similar results[65].

Unfortunately, this literature does not distinguish between the productivity impact of a carer that benefits from short breaks or a carer who is highly stressed compared to a carer not in receipt of short-breaks or who is feeling less stressed. As such, it is not possible to quantify this relationship at this time.

We do explore the potential impact of presenteeism as part of our sensitivity tests based on the general finding that the scale of presenteeism impacts for those suffering from mental health challenges is likely to be around two times the impact of absenteeism[66].

---

[61] Harper, A., Dyches, T. T., Harper, J., Roper, S. O., & South, M. (2013) Respite Care, Parent couples Quality, and Stress in Parents of Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, *43*(11), 2604-2616

[62] Norton, M., Dyches, T. T., Harper, J. M., Roper, S. O., & Caldarella, P. (2016). Respite care, stress, uplifts, and parent couples quality in parents of children with Down syndrome. *Journal of Autism and Developmental Disorders*, *46*(12), 3700–3711. For other articles with similar results, see Robertson, J., Hatton, C., Emerson, E., Wells, E., Collins, M., Langer, S., & Welch, V. (2010). The impacts of short break provision on disabled children and families: an international literature review.

[63] Bourreau-Dubois, C., & Doriat-Duban M. (2016). Covering the Costs of Divorce: The Role of the Family, the State and the Market. *Population*, English Version, *71*(3), 457-477.

[64] Giovannetti, E. R., Wolff, J. L., Frick, K. D., & Boult, C. (2009). Construct validity of the Work Productivity and Activity Impairment questionnaire across informal caregivers of chronically ill older patients. *Value in Health*, *12*(6), 1011-1017.

[65] Mazanec, S. R., Daly, B. J., Douglas, S. L., & Lipson, A. R. (2011). Work productivity and health of informal caregivers of persons with advanced cancer. *Research in nursing & health*, *34*(6), 483-495.

[66] Centre for Mental Health (2017): Mental health at work: The business costs ten years on: https://www.centreformentalhealth.org.uk/publications/mental-health-work-business-costs-ten-years#report