

Carers Strategy Team  
Department of Health  
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29 July 2016

Dear Carers Strategy Team

Following the invitation from former minister Alistair Burt MP during the Westminster Hall debate on support for children with life-shortening conditions on 7 June, I enclose a short response to the carers strategy consultation. While I acknowledge that your preferred means of receiving responses is by questionnaire, I am keen to convey the needs and wishes of the many carers who Together for Short Lives represent.

Together for Short Lives is the UK charity that, together with our members, speaks out for the 49,000 children and young people in the UK who are expected to have short lives. Together with everyone who provides care and support to these children and families, we are here to help them have as fulfilling lives as possible and the very best care at the end of life. We can't change the diagnosis, but we can help children and families make the most of their time together. Sixty of our members are from the voluntary sector that deliver children's palliative care - including children's hospices and other service providers.

The number of children and young people with life-shortening conditions is increasing. Worryingly, however, this number is not being monitored and the demand for services to meet their needs is not being met. The complex support which they and their carers need from multiple agencies and professionals is not joined up enough and families are having to fight to get the services they need. These problems are exacerbated when young people transition from children's to adults' services. We routinely hear from families that they fail to get the information they need about what help and support is available locally. We have found a low level of awareness about the services available to children and families in many areas.

Carers face a postcode lottery of support across England, and the services which support them are funded neither equitably nor sustainably. Local authorities have cut their short breaks spending since 2010, which has had a direct impact on families; only a minority of families with disabled children believe that they can access the short breaks they need. Services also struggle to find enough staff with the skills and experiences needed to support carers of children with life-shortening conditions.

Babies and young children under the age of three with life-shortening conditions often depend on ventilators, large and heavy equipment or other types of technology to stay alive. Yet their carers are ineligible for an important benefit, the disability living allowance (DLA) mobility component, which would help give them access to the specialist transport they rely on.

We believe that there is much that the government can do to improve support for carers of children and young people with life-shortening conditions:

1. We would like the government to help us make sure that all those who come into contact with carers of children and young people with life-shortening conditions (on a professional or personal basis) are able to let them know that support that is available to them and about how to access it.

2. We would like the government to hold local authorities to account to increase funding for short breaks for disabled children and their families. These providing vital respite and support that in the long term saves the state money by reducing the number of hospital visits as well the incidence of family breakdown.
3. We would like the government to change the eligibility criteria for the mobility component of Disability Living Allowance so that 0-3-year old children with life-shortening conditions dependent of heavy or bulky medical equipment can access adapted vehicles.
4. We would like the government to set out what steps can be taken to make sure that there are enough people with the skills, knowledge and competencies needed to care for children with complex and life-shortening conditions. We want to make sure that all professionals who come into contact with children with life-shortening conditions are trained in children's palliative care - and that their skills and knowledge are maintained and refreshed during their careers.

Please do get in touch should you have any queries about our response or would like further information. I would be very happy to meet with the team to discuss any of the issues we have raised in more detail.

Yours sincerely

**Shaun Walsh**  
**Executive Director of External Affairs**