

# Summary of Recommendations from the Carer Research Advisory Panel

Overarching principles	Theme specific recommendations
<p><b>1) Awareness raising</b>            Many good services exist but are not effectively communicated to carers in an timely manner in ways that meet their needs</p> <ul style="list-style-type: none"> <li>• Make carers aware of the support services available to them or the person they are caring for</li> <li>• Raise awareness among health care professionals of the need to address the impact of end of life caregiving on carers</li> </ul>	<p><b>1) Patient condition</b>            Carers are likely to experience better mental health if the following are in place</p> <ul style="list-style-type: none"> <li>• Accessible and timely information about the patient's end of life condition.</li> <li>• Control of the patients' symptoms.</li> <li>• Recognition that palliative patients may have other conditions that are still treatable e.g. requiring dentists and opticians, and continued referral to for these to appropriate care that accommodates their changing mobility.</li> <li>• Holistic approach to patients' treatment and care.</li> <li>• Co-ordinated and continuous, rather than fragmented, patient care:               <ul style="list-style-type: none"> <li>○ Carers should not need to tell their 'story' repeatedly. They may e.g. benefit from having a folder with all relevant patient information that can be taken to appointments</li> <li>○ Provision should not depend on where the carer lives</li> <li>○ Patients should be able to see the same GP over the course of end of life care</li> </ul> </li> </ul>
<p><b>2) Road Map to support carers to navigate the end of life caregiving journey</b></p> <ul style="list-style-type: none"> <li>• Provide carers with a 'road map' with all the relevant information to prepare and support them to navigate each stage of end of life caregiving and bereavement. This needs to be holistic and include:           <ul style="list-style-type: none"> <li>○ Information on what help is available locally</li> <li>○ Information on how to access specialist equipment and services for the patient at home</li> <li>○ Information relating to practical advice, which might include: legal advice and making a Power of Attorney; financial advice; service advice</li> <li>○ Lists of useful telephone numbers, websites, and email addresses</li> </ul> </li> </ul>	<p><b>2) Impact of Caring Responsibilities</b></p> <ul style="list-style-type: none"> <li>• Carers should be able to spend quality time with the person they are caring for and have sufficient time for caregiving, and their own concerns. Helping carers with coordination, administration and navigation through stages of the journey end of life caregiving would help free up time their time and reduce the impact of caring responsibilities on them.</li> </ul>

**3) Bespoke support which recognises the carer has needs and identifies them through assessment**

This should reflect that carers' needs are holistic and support should be tailored where possible to the needs and personal circumstances of individual carers:

- Service providers should recognise that carers have needs and use appropriate tools to assess them.
- Needs assessment should be comprehensive, include assessment of medical, personal and social needs, and take into account the carer's actual needs, rather than just what services can offer.
- Services should take into account the carer's personal circumstances when looking to support carers

**3) Finances**

This was a fundamental issue that overlaps with overall recommendations for Practical considerations/

- Carers should not be financially disadvantaged by their caregiving role and need (as an absolute minimum) sufficient finances (e.g. through a decent carers allowance, where eligible) to ensure basic needs are met, including ability to pay rent, bills and 'put a decent meal on the table'.
- Carers should have access to practical advice, including early legal and financial advice, including Power of Attorney, will making and Do Not Resuscitate where appropriate.
- Carers should receive timely advice on their eligibility for funding for care costs, including their eligibility for a housing adaption grant

**4) Standardized comprehensive assessment to assess 'actual' rather than 'managed' needs of the patient**

To help ensure that the person cared for receives the support they need, carers' role in achieving this is understood, and carers feel able to manage caregiving tasks:

- Patients should be assessed for their 'actual' needs as opposed to their 'managed' needs, to make visible all the support the carer provides, ensure the assessment does not conclude that the patient is more capable than they really are, and that their dependency on the carer's support is fully recognised.
- Assessment should be standardized across services and provide a comprehensive assessment of the patient's actual needs.

**4) Relationships**

While acknowledging that carers may vary in their feelings about being a carer and in the quality of the patient-carer relationship

- Carers should be enabled to spend adequate time with the patient. Easing navigation through each stage of the journey of caregiving would take pressure off carers and free up time for them to do so.

### ***5) Coordinated and timely care by providing a single point of contact for the carer***

Carers do not necessarily know how to navigate the health and social care system, and will need support in articulating their specific needs:

- Provide carer access to a key worker as a single point of contact, to ensure patient care is timely, continuous, and that care of both the carer and the person they are caring for is coordinated. This support should extend to:
  - Comprehensive assessment of needs
  - Helping carers with administrative tasks e.g. filling in necessary forms
  - Signposting and/or referral to the relevant services
  - Follow up by relevant services, including post bereavement.
  - Advocacy support to help carers articulate what they need.

### ***5) Carer Internal Processes***

Recognising that some carers may need 'permission' to feel the way they feel:

- Carers need to have an outlet for 'venting emotions'.

**6) Practical considerations/Essential Resources:**

This needs to take into account that carers have to self-declare to be recognised as a carer, which can be difficult for some; that they may not live in the same household as the person cared for, and that time is of the essence for end of life caregiving.

As a minimum:

- Carers need to feel safe in the knowledge that their basic physical needs will be met, both during end of life caregiving and post-bereavement.
- Carers should not be financially disadvantaged by their caregiving role and need sufficient finances for basic needs (see Finances).
- Equipment for the patient should be easily accessible and timely provided, not when the patient no longer requires it. Equipment should be retrieved in a prompt and sensitive manner following death.
- Carers should have access to practical advice, including legal and financial advice (see Finances)
- Carers should be given timely advice on their eligibility for funding for care costs (see Finances).

**6) Support**

(a) Recommendations about support for the patient  
Given that carers are more likely to experience better mental health when the cared for person receives the care and support they need:

- Support for patients should be readily available, responsive, accessible and flexible.
  - With the option of receiving support at home or close to home wherever possible
  - With home care services flexible and responsive to the patient’s needs, including timing of visits.
- Joint support should be available the carer and the person cared for if that is their preference.

(b) Recommendations about support for the carer

- Service providers should recognise that carers have needs and use appropriate tools to assess them. Assessment should be comprehensive and take account of the carer’s actual needs, not just what services can offer.
- Individual formal carer support should be available.
  - Carers should be able to receive general counselling if they need a safe space to ‘vent’
  - Carers should be permitted to remain in the system post-bereavement for bereavement counselling and other support services.
- Individual informal carer support should be available
  - Carers should have early access to local support/ peer support groups, which may also help identify further sources of help/support

**7) Contextual factors**

All recommendations should take into account the specific context, personal circumstances and preferences of individual carers, wherever possible.