

# SUPPLEMENT 1: RECOMMENDATIONS FROM CARER RESEARCH ADVISORY PANEL (DETAILED VERSION)

## RESEARCH ADVISORY PANEL DELIBERATIONS

The recommendations developed by the Carer Research Advisory Panel (RAP) are based on the following reflections and considerations in relation to the research evidence considered:

- The RAP discussed the importance of the relationship between the carer and the person they are caring for. It was noted that while the patient condition impacts on the mental health of the carer, the RAP recognises there is little that carers can do to change the patient's condition. Taking this into account, RAP recommendations are based on making things as easy as possible for the carer, and removing obstacles which might stop them being a better carer. This includes removing/reducing unnecessary demands on the carer's time to allow more time for the carer to look after the person they are caring for. The RAP considered this to be very important because the perception that they might not be offering the optimum care could have a significant impact on carer's mental health.
- The RAP discussed the importance of carers feeling empowered, having their voices heard, and having proper engagement with services as active participants within their caregiving role. The RAP considered these to be important aspects in maintaining and improving carer mental health.
- The RAP recognises that the circumstances and experiences of individual carers are likely to vary and that *'one size does not fit all'*. This may extend to carers experiencing different feelings about being a carer, as well as differences in the dynamics of the patient-carer relationship. Taking individual circumstances into account, RAP recommendations are based on overcoming what the RAP considered to be common challenges experienced by end of life carers that may help to support the mental health of the majority of those carers.
- The recommendations were based on a desire to support carers to maintain and/or improve their mental health, and not *'make things worse'*.
- The RAP noted the importance of considering the mental health of bereaved carers, alongside the mental health of end of life caregivers. Where appropriate, the recommendations should take into account the end of life caregiving journey post bereavement.
- The RAP recognised the need to be pragmatic in relation to the recommendations they could develop based on limits of what services can provide, and therefore focused on what might be changed to support carer mental health.
- The seven specific themes identified from the research evidence as affecting carers' mental health were informed by the RAP discussion. These were: patient condition, impact of caring responsibilities (e.g. workload, life changes), quality of relationships, finances, carers' own internal processes (e.g. carers' belief in their own ability, coping strategies), formal/informal support and contextual factors (e.g. age, gender). While the RAP agreed that these are useful

way of presenting /grouping the evidence, they acknowledged that these themes are not a comprehensive account of what influences carers' mental health. The RAP specifically noted gaps in the research evidence in relation to personal identity and the experience of grief.

- The RAP discussed the challenge of developing recommendations around the seven specific themes identified from the research evidence. In the light of these, RAP members focused on developing recommendations which reflected the full extent of the end of life caregiving journey.
- We therefore first present what can be termed 'Overarching principles' which refer to recommendations which extend across all seven themes identified from the research evidence. Next, we present recommendations that have been placed under specific themes (presented as 'Theme specific'). These reflect those recommendations which 'fit' with the themes from the research evidence, rather than a comprehensive list of recommendations developed for each theme.

# RECOMMENDATIONS

## Overarching principles

### *1) Awareness raising*

The RAP recommends the following, acknowledging that while there are many good services available, these are not always effectively communicated to carers in a timely manner in ways that meet their needs and personal circumstances:

*a) Carers are made aware of the support services available to them or the person they are caring for*

- Carers should be made aware of the local services (including private sector and social services) that are available for people they are caring for e.g. local dentist or opticians or where to go to obtain a wheelchair for the person they are caring for.

*b) Raising awareness among health care professionals of the need to address the impact of end of life caregiving on carers:*

- Health care professionals should have a greater awareness of the need to address the impact of end of life caregiving on carers, including recognising that carers' needs extend into bereavement.

### *2) Road Map to support carers to navigate the end of life caregiving journey/process*

The RAP recommends the following, noting that the end of life caregiving journey extends into bereavement:

- Carers should be provided with a 'road map' containing all the relevant information to prepare and support them to navigate their way through each stage of the journey/process of end of life caregiving. This road map needs to be holistic in approach and include:
  - Information on what help is available locally for carers and where carers can go to get this help. This needs to include information on local services (including private sector and social services) available for the person they are caring for and be holistic in nature
  - Information on how to access specialist equipment (e.g. wheel chairs, hospital beds, hoists, continence pads) and services (e.g. physiotherapy) for the patient at home
  - Information relating to practical advice, which might include: legal advice and making a Power of Attorney; financial advice; service advice
  - Lists of useful telephone numbers, websites, and email addresses.

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

The RAP recommends the following, recognising that: carers' needs are holistic and extend to medical, personal and social needs; and that support should be tailored where possible according to the needs and personal circumstances of individual carers:

- Services 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.

#### ***4) Standardized Comprehensive Assessment to assess 'actual' needs of the patient***

The RAP recommends the following, to ensure that the person the carer is caring for receives the care and support they need, and that the carer's role in achieving and maintaining this is understood, as carers' mental health is likely to be better when the patient is well supported and carers' feel able to manage the caregiving tasks:

- Patients should be assessed for their 'actual' needs as opposed to their 'managed' needs. Actual needs assessment should take into account all the support the carer currently provides to the patient e.g. making meals and food shopping, to ensure the assessment does not conclude that the patient is more capable than they really are, with their dependency on the carer's support being fully recognised.
- Assessment should be standardized across services and provide a comprehensive assessment of the patient's actual needs.

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

The RAP recommends the following, based on their recognition that carers do not necessarily know how to navigate the health and social care system, and will need support in articulating their specific needs:

- Carers should be given access to a key worker (who may or may not be a healthcare professional) as a single point of contact, to ensure patient care is timely, continuous, and that the care of both the carer and the person they are caring for is coordinated. This support should extend to:
  - Comprehensive assessment of needs, including medical, personal and social needs
  - Helping carers with administrative tasks e.g. filling in necessary forms
  - Sign posting and/or referral to the relevant services to assist with the carer's needs
  - Follow up with relevant services, including post bereavement.
  - Advocacy support to help carers articulate what they need.

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

The RAP felt this was a fundamental factor which needs to be addressed. It takes into account the following: that carers have to self-declare to be recognised as a carer, which can be difficult for some; that carers will not necessarily live in the same household as the person they are caring for; and that time is of the essence for end of life caregiving.

As a minimum, the RAP recommends the following, taking into account that carers are more likely to experience better mental health when the person they are caring for is receiving the care and support they need, and when demands on the carer's time is reduced:

- 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 are not financially disadvantaged by their caregiving role and are given (as an absolute minimum) sufficient finances (such as in the form of a decent carers allowance, where eligible) to ensure their basic needs are being met. These include the ability to continue to pay rent, bills and 'put a decent meal on the table'.
- Equipment for the patient should be easily accessible, be provided in a timely manner, not arriving after the patient no longer requires it. Retrieving equipment following death needs to be handled promptly and sensitively.
- Carers should be given access to practical advice, including early legal advice and financial advice about matters such as obtaining a Power of Attorney, will making and Do Not Resuscitate where appropriate.
- Carers should be given timely advice on their eligibility for funding for care costs, including their eligibility for a housing adaption grant with timely follow up, where relevant to the carer's circumstances.

## Theme specific recommendations

### *Patient Condition*

The RAP recommends the following, based on their recognition that carers are more likely to experience better mental health when the person they are caring for is receiving the care and support they need:

- Relevant information about the patient's end of life condition should be made accessible, in a timely manner.
- The patients' symptoms should be controlled.
- Health care professionals should recognise that palliative patients may have other conditions which are still treatable e.g. patient may still require access to dentistry services and opticians.
- Patients who require treatment and care for conditions not palliative in nature should continue to be referred to appropriate care that accommodates the patient's changing mobility.
- Patients' treatment and care should be holistic in approach.
- Patients' care should be co-ordinated, and continuous, rather than being fragmented.
  - Carers should not need to tell their 'story' repeatedly. This could be addressed by providing the carer with a folder which holds all the relevant patient information which they can take along with them to appointments
  - Provision should not depend on where the carer lives
  - Patients should be able to see the same GP over the course of end of life caregiving.

## *Impact of Caring Responsibilities*

The RAP recommends the following:

- 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 some of the coordination and administration and making it easier to navigate their way through each stage of the journey/process of end of life caregiving will help to free up time for the carer and help to reduce the impact of caring responsibilities on them.

## *Finances*

The RAP felt this was a fundamental factor which needs to be addressed. This needs to take into account the following: that carers have to self-declare to be recognised as a carer, which can be difficult for some; that carers will not necessarily live in the same household as the person they are caring for; time is of the **essence for end of life caregiving. As a minimum, the RAP recommends the following:**

- Carers should not be financially disadvantaged by their caregiving role and should be given (as an absolute minimum) sufficient finances (such as in the form of a decent carers' allowance, where eligible) to ensure their basic needs are being met. These include the ability to continue to pay rent, bills and 'put a decent meal on the table'.
- Carers should have access to financial and other relevant advice, which might include early legal advice about decisions ahead and making Power of Attorney where relevant to the carer's circumstances.
- Carers should be given timely advice on their eligibility for funding for care costs, including their eligibility for a housing adaption grant with timely follow up, where relevant to the carer's circumstances.

## *Relationships*

The RAP recommends the following, while acknowledging that carers may experience different feelings about being a carer and recognising that the quality of the patient-carer relationship may differ:

- Carers should be enabled to spend adequate time with the patient. Making it easy for carers to navigate their way through each stage of the journey/process of end of life caregiving without 'trailing from pillar to post' will help to take the pressure off carers and free up time for the carer to spend more time with the person they are caring for.

## *Carer Internal Processes*

The RAP recommends the following, recognising that some carers may need 'permission' to feel the way they feel:

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

## Support

### (a) Recommendations about support for the patient

The RAP recommends the following, based on their recognition that carers are more likely to experience better mental health when the person they are caring for is receiving the care and support they need:

- Support for patients should be readily available, responsive, accessible and flexible.
  - Carers should have the option of receiving support for the patient at home or close to home rather than having to travel to a hospital or GP to get it, wherever possible
  - Home care services for the patient should be flexible and responsive to the patient's needs and take into account the time of visits that meet the needs of the patient. Patients should not have to cancel all visits scheduled for the day just because they do not want the first visit in the morning when the morning does not suit the patient.
- Dyadic (joint) support should be available for both the carer and the person they are caring 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 address them. Assessment should be comprehensive and take account of the carer's actual needs, not just what services can offer.
- Individual formal support should be made available for the carer.
  - Carers should be able to receive general counselling services when they need a safe space to 'vent'
  - Carers should be permitted to remain in the system after palliative care services have been withdrawn in order to receive post-bereavement counselling and other support services post-bereavement.
- Individual informal support is available for the carer.
  - Carers should have early access to local support/peer support groups. These can also help carers to identify further sources of help/support they might not otherwise hear about.

## Contextual factors

The RAP recommends that all recommendations take into account: the specific context; personal circumstances; and preferences wherever possible, of individual carers.