

SUPPORTING INFORMAL CARERS DURING THE COVID-19 PANDEMIC

The below is a working list of things to be aware of/ consider in supporting informal carers (family and friends who support patients in an unpaid role) impacted by COVID-19. This is partly evidence-based and partly grounded in our combined experience of working in applied research on informal carer support needs.

CARER CONCERNS during COVID-19 outbreak

ROLES AND TASKS

- ...many people will have been thrown into the role of caring for someone (and all that entails) rapidly and come unprepared for the role.
- ...pre-existing long-standing carers (e.g. for those with long-term conditions) may see their role change as new caring tasks are required e.g. management and impact of self-isolation on both the patient and the carer.
- ...carers will have to manage new or exacerbated COVID-19-related symptoms of breathlessness, cough, fever etc.

UNCERTAINTY

- ...carers' greatest source of anxiety and distress is not knowing what to expect or what is likely to happen, or not understanding what is happening currently.

BEING ABLE TO PROVIDE CARE

- ...the concern of carers will (rightly) be about the patient but they need to take care of themselves as well – both for their own health and in order to continue caring.
- ...carers need to decide on their level of contact with the patient (e.g. what is harmful and what is helpful) where they are not already living with the person cared for.
- ...potential infection of long-standing carers with COVID-19 will have major impact on the caring role/patient if there is a (temporary or complete) loss of a primary pre-existing carer.

BEREAVED CARERS

The impact on carers of a sudden bereavement from COVID-19 may include...

- ...not being able to be with the patient at the end.
- ...coping with bereavement when the carer may be self-isolating during first weeks post-bereavement.

IMPLICATIONS/ POTENTIAL ACTIONS FOR CLINICIANS

- Practitioners need to ensure they know who the patient's carer(s) is/are in order to support both the carer and the patient – if possible, ask the patient "who gives you help and support at home?" (as not everyone recognises the term 'carer').
- Monitor the level of informal carer support available (including when a carer is no longer able to support the patient for whatever reason).
- Assess what carers need to enable them to (continue to) care e.g. information about managing COVID-19 related symptoms (e.g. breathlessness can be particularly distressing).
- Have available short, clear, consistent information on the effect of the virus on the lungs – this is different from regular pneumonia.
- Ensure carers have a means of accessing prescribed medications (new and pre-existing), as well as supplies and equipment if they cannot go out.
- Remind carers to look after and monitor their own health.
- Give clear advice for carers who think they may be becoming ill e.g. who they should contact if they are unable to manage to look after the ill person (whether due to the virus or existing conditions).
- Give guidance on management of any required self-isolation.
- Give guidance on level of contact with the person cared for.
- Ensure carers are fully informed from the outset and that they understand what is happening and why, and what to expect.
- An essential for carers is knowing who to contact when concerned (a person, not an answering machine).
- Longer term, carers are likely to value the establishment of a carer-dedicated (ideally local) manned, free-of-charge helpline.

BEREAVED CARERS

- ...there needs to be a bereavement management plan to support those bereaved in these circumstances
- ...it could be helpful to involve people with expertise in supporting those bereaved in comparable circumstances e.g. when bereaved and deceased have been isolated from each other through distance or circumstance (e.g. prison)