section 4.3: including caregivers in discharge planning

considering the role of caregivers & families

Despite the inclusion of community supports in the care of those facing a terminal illness and living at home, caregivers provide the majority of care, often 24 hours a day. Caregivers consist of family and friends – the partners, parents, siblings, children and friends of the patient, and they are usually not trained professionals in health care or personal care. They are potentially affected physically, emotionally and financially by their decision to help with the provision of care at home and will need a clear understanding of what this commitment means.

Many caregivers believe that they should be available all day, every day, that they are obligated to provide this kind of help and that there is no-one else willing to carry out this role.[1] Some of the challenges faced by caregivers include the need to negotiate a complex health system which is likely to involve many agencies, insufficient skills to manage patient symptoms, limitations of age (25% of caregivers in Australia are older than 65[2]), and for some, the need to combine ongoing formal employment with a primary caring role. Despite these challenges the majority of caregivers readily identify positive aspects of the role.[3]

Fundamental requirements for caregivers include:

- a clear understanding of what is required in providing care
- information and education to assist them in tasks that often completely unfamiliar and may be quite complex[4]
- an indication of the stage of the patient's disease and of the length of time that they will be providing care
- a contingency plan should care at home not be sustainable.

It is essential that caregivers have the opportunity to ask questions of the health care team and to be provided with open and honest answers, which may be realistically balanced against "sometimes we don't know".

A number of considerations which relate to the caregiver have already been raised in Section 4.2 – *Discharge home to metropolitan Adelaide*.

specific caregiver requirements

Involvement in decision making and information sharing

- identify the key caregiver who will be involved in all discharge planning
- consider holding a family meeting to share information, involve key people and identify practical and logistical difficulties, eg caregiver with a severe back injury or additional responsibility for elderly parents
- allocate time to realistically outline the patient's needs, current symptoms and their interpretation in the context of disease, eg lethargy, confusion, anorexia and weight loss or other likely symptoms that may occur following discharge
- advise the caregiver of the community supports available, their role and any costs that will be incurred
- include the caregiver in home assessments, eg OT – see Section 2.1.1 – *The role of the multidisciplinary team*

Hands on education and participation in providing personal care provided by appropriate staff (including nursing, physiotherapy, occupational therapy)

personal care

- bed mobility – lifting, safe transfers, use of slide sheets
- assisting with sponging or showering, positioning for comfort in bed
- skin care, maintaining skin integrity, avoiding pressure sores, types of creams that can be used
- mouth care
- management of continence, changing of linen
- management of any wounds/ stomas, if this is required

implementing safe transfers

- bed to chair
- chair to commode
- transfers from the car
- is the caregiver able to transfer the patient in and out of a car? – if not, are they aware that they may access handicapped parking and access cabs? – forms available from hospital social worker or local GP
- use of mobility aids such as walking sticks or frames (with supervision and instruction from the physiotherapist)

Accessing ongoing supplies of equipment

- is the caregiver aware of how to access ongoing supplies of equipment such as incontinence pads, stoma supplies?
- is the patient a member of the stoma/ileostomy group?

Medications

- understanding of timing/ need for diary/route and admin
- can medications be crushed, if so which ones?

Additional specific instructions which are required for home care

- specific dietary modifications or swallowing difficulties, eg texture, need to vitamise

Instructions about the use of specific equipment

- are nebulisers, suctioning machines, gastrostomy feeding machines, lifting machines, oxygen concentrators, etc required and has education about their use been provided?
- what action will the family take should a power failure occur and the concentrator cease to function – does the family have access to oxygen cylinders or will the patient need to present to the closest emergency department?
- are caregivers familiar with the use of continuous infusion pumps or gastric feeding machines – what to do should it alarm – are they already known as clients of RDNS and have access to their 24-hour contact number?

Modifications in the home

A home assessment by the hospital occupational therapist or domiciliary care (if after discharge) can provide valuable information about the patient and caregiver's requirements for home modifications:

- have caregivers had the opportunity to become familiar with the equipment provided for home care (eg hospital bed)?

- are the caregivers aware that cutting down single sheets to make draw sheets may be helpful?
- does the caregiver require and have access to a mackintosh or plastic sheeting?

Managing the emotional and spiritual needs of the patient

- does the caregiver feel able to respond to the patient as they adjust to terminal illness and questions relating to the meaning of life?
- has the caregiver been given a private opportunity to express their concerns or anxieties about managing their own emotional load, in tandem with that of the patient?

Role of community based services

- is the caregiver clear about the roles of community based services which are being considered by the hospital staff, or will be put in place following discharge, including information about planned home visits and any fees required?

Linking caregivers with appropriate hospital staff

- has the caregiver had contact with staff who can support streamlined discharge, eg Discharge Planner/Case manager, Aboriginal Liaison or Rural Liaison staff , Transitional care staff, RDNS Liaison Nurse, Hospital at Home staff, Ethnic Link?

Contact plan

- does the caregiver have instructions for contacting health professionals or accessing respite at short notice? – who to contact and in what order. Does the caregiver have a listing of contact numbers clearly marked on a card on the refrigerator?
- has an alternative plan been discussed should care needs change or be beyond caregiver capacity or community resources?
- have local support networks been identified including family, friends, local clubs, church groups? – would a practical roster system with a diagram outlining day to day tasks and how these might be shared with the identified supports be helpful? (eg meal preparation, brief respite or companionship, shopping)

Financial and legal considerations

Costs borne by families in terms of possible loss of employment, cost of medications, petrol for transport to medical appointments, investigations, hire of special equipment, increased electricity and water costs are high.[5]

  - does the patient and/or caregiver have an identified source of income? – have the forms for Centrelink's caregiver payment or benefit been provided?
  - are the family and caregivers aware that Centrelink can provide information and assistance?
  - does the patient or caregiver require information about superannuation, accessing leave from employment, or sickness benefits?
  - do advance directives, access to bank accounts or wills need to be addressed?

Caregiver supports

Caregivers are at risk of poor physical and emotional health, with the stressors associated with caring often seen as cumulative and increasing over time[6], and have increased rates of depression and anxiety.[7] Encouraging caregivers to plan for their own exercise and recreation, to recognise the signs of fatigue (both physical and emotional) and providing information about availability of other options of care is essential. Caregivers may also prefer to discuss their needs in the absence of the person receiving care.[8]

- what informal supports does the caregiver already have? – friends, family, sporting, church or charitable group membership
- is there a local or disease specific group who can offer peer support, shared experiences, assistance with problem solving and coping strategies?
- is the caregiver aware of Carers SA or Carer Support and Respite programs?
- is the caregiver aware of respite options?
- are day care options or supports from the council available locally?
- is there an understanding and acknowledgement by both the patient and the caregiver of the impact of providing round the clock care, and that this level of care may not always be sustainable?
- would the input of a volunteer be of benefit?- see Section 2.9 –*The role of volunteers*

Specific information is available from the hospital social worker, discharge planner and local councils.

Instruction provided can be followed up by community based support staff, including RNDS or other community nursing and domiciliary care staff.

related resources and information

See Section 5 – *Accessing resources for care*

Livingcaringworking website – www.livingcaringworking.com

Additional resources at **CareSearch** in caregiver supports section – see www.caresearch.com.au.

references

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[3] Hudson P (2004) Positive aspects and challenges associated with caring for a dying relative at home. *International Journal of Palliative Nursing*. Vol 10 (2), 58-65.

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[8] Hudson P (2004) Positive aspects and challenges associated with caring for a dying relative at home. *International Journal of Palliative Nursing* Vol 10, (2), 58-65.