Responding to policy guidance on supporting carers

Carers Conference  2nd March 2016
Dr Ros Taylor
Clinical Director Hospice UK
@hospicedoctor
Family Caring

The work of

– Kelli Stajduhar
– Serge Dumont
– Nancy Guberman
– Peter Hudson
– Gunn Grande & Gail Ewing
– S Robin Cohen
– Sheila Payne
Canada

80% patients want to die at home.

Only 50% of their relatives support this

Only 5% of these relatives felt they had the skills and knowledge to care

_N. Guberman (2006)_
Families' Values and Attitudes Regarding Responsibility for the Frail Elderly
Journal of Aging & Social Policy 18(3-4)
There are 6.5 million carers in the UK today. That’s 1 in 8 adults.

This unpaid care saves the state £119 billion a year.
£132 billion is close to the total annual cost of health spending in the UK, which was £134.1 billion in the year 2014-2015.

The support provided by the UK’s carers in 2015 saves the public purse £2.5 billion per week.
Family Care or Family Scare
8760 hours in a year
Before becoming a carer, are you a "don’t carer"?!?

**JOB DESCRIPTION**

**Post:** Full time Carer

**Hours:** Up to 24 per day, 7 days per week, 52 weeks per year. **Remuneration:** This post is voluntary but is often fitted around full-time employment

**No application process required:** No interview necessary; This is an automatic appointment.

**Skills required:**
- The Carer must be able to cook, clean, launder, provide basic nursing care and act as chauffeur or transport manager in addition to keeping the garden tidy, organising the diary and if necessary the household accounts.
- The Carer must be a willing companion and divert the patient from the stress of illness, answer the phone, edit health bulletins, and host visits from friends and numerous health professionals.
- The Carer must learn to work and maintain any specialist medical equipment provided and fully understand the properties of all the drugs prescribed.
- Advice from the dietician must be followed and meals must be varied in content and attractively served.
- The Carer must be prepared to investigate and access services available since the existence of such facilities is not always obvious.
- The Carer must sit in on medical appointments and where necessary, absorb bad news and remember all that is said for future reference – at this point an upbeat and positive attitude must be adopted.
- The Carer must keep fit and maintain high energy levels regardless of number of hours of sleep available. The need for an inexhaustible reserve of emotional strength is essential.
- A sense of humour is an optional extra but is highly recommended!
What do Family Carers do?

Tasks of daily living – cook, shop, bills, travel
Clinical tasks – injections
Personal care – toileting, dressing, bathing
Accompany
Co-ordinate care
Find information
Spokesperson
Notice deterioration

??? REPLACE PROFESSIONAL
SPECTRUM

From

PRESENCE and SAFETY

To

DELIVER and CO-ORDINATE CARE
Status of family caregiver is **VAGUE**

- They give 75% care…but don’t appear in statistics

No case files …

Need tools to assess needs and burden
The unit of palliative care is ‘the family’
How are families supported in hospice?
What makes the difference in hospices?

Range from 1:1 support to gardening groups to coaching to drop-in etc
Is it the relationship?
Is is the service?
Is it the cup of tea?
Is it the information?
Families are recipients of care
Families are providers of care

Competing feelings of
- LOVE
- OBLIGATION
- KINSHIP
Assumptions & Expectations
Implicit assumption that family caregivers willingly choose the carer role

Examining the perspectives of family members involved in the delivery of palliative care at home.
Journal of Palliative Care 19(1) 27-35.
Desire (or not) to be an Equal Member of the Hospice/Palliative Care Team

*Stajduhar K, Nicol D, Martin W, & Funk L.(2008)*
*Situated/Being Situated: Client and Co-Worker Roles of Family Caregivers in Hospice/Palliative Care.*
Family Carers *Situating Themselves as Co-Workers*

Integral member of team

Primary caregiver - leadership role

Confident and competent

Often hard to assert self when they knew best
What if……
We trusted families to care and coached them ….
Family Carers *Being Situated by others* as Co-Workers

Not prepared

Frustrated at being placed in a position of managing complexity

Terrified
Care at home

.....should be a decision that is negotiated and renegotiated based on continual assessment of the family carer’s position
Need a **moral escape hatch** to avoid broken promises
Family Caregiver Burden

Serge Dumont
67% family carers have a high level of distress

Burden is related to
– Satisfaction with help
– Perceived self competence
– Opportunities for meaning
– Relationship with patient

Dumont S  BURDEN SCALE  (2008)
Journal of Palliative Care 24:3 151-161
Abel J. Compassionate community networks: supporting home dying.
BMJ Supportive and Palliative Care 2011; 1:129-133
Jean

Jake
Son

Lucy
Daughter

Dave
Husband

Adapted from Macy J. Active Hope. New World Publishing 2012: California
New question

What would it take to help you die at home and what can you, your family, friends and community bring to that?
Public health approach to palliative care

The work of

– Allan Kellehear
– Julian Abel
– Libby Sallnow
BABY BOOMERS - That’s us……
EXPECT to BE EQUAL PARTNERS in CARE

WONT MAKE SAME SACRIFICES

N. Guberman (2012)
Baby Boom Caregivers: Care in the Age of Individualization

www.hospiceuk.org
Can't we talk about something more PLEASANT?

ROZ CHAST
A MEMOIR

#1 NEW YORK TIMES BESTSELLER

NATIONAL BOOK CRITICS CIRCLE AWARD WINNER

NATIONAL BOOK AWARD FINALIST

10 BEST BOOKS
The New York Times Book Review
2014
Policy response…..
Map social universe
Don’t assume…
Assessment is key
Coach and information
Community response
You told me you'd spend your whole life trying to make me happy.

I didn't expect to live this long.