

## **Issues for carers**

Work/caring balance, (are carers allowed to have a life outside caring?)

No respect. Accused of wrapping daughter in cotton wool.

Being a daughter not just a carer.

Worry about future, what happens when I die?

Finding a job after caring stopped.

Coping with my losses.

Dealing with personal guilt, society's attitude to disabled people.

Tick-Box assessments: Human beings cannot be reduced to tick boxes, RETHINK and no secrecy.

Deciding our next step – learning from our work.

Adapting to 'Role' change, i.e. equal to parental.

Quality of care = quality of life for patient = quiet mind and quality of life for carer.

Justice/ injustice, wrong doing in health care by professionals.

System is inflexible and tendency to 'Cover up.'

Physical challenges – Tiredness, self – denial, domestic violence.

Looking after the house and garden to a high enough standard.

Access to information – services, equipment.

Right to respite as integral part of care package, more respite at home.

Lack of information of what is available and what rights carers have.

Advocates are treated with more respect than carers.

To put one's own goals on the side, i.e. career, but, tie transferable skills related to caring.

Red tape, constant battle.

Major barrier socially talking about it to friends/ family.

Not being taken seriously.

Carers should let their voice be heard loudly.

All these initiatives involve 'managerial' staff who are all beginning to understand. The problem lies with front line staff e.g. GP's, nurses, consultants – they have no interest in carer's issues.

Dual diagnosis, hard to get coordinated support.

Not knowing where to go for advice and assistance.

How do I know what questions to ask?

Communication – between, with in, organisations.

Mental – Tiredness, patience & self-control, self-denial, no social life.

Advice to be improved : managing incontinence and other disabilities, moving and handling.

Money: Lack of, inequity of, extra costs of caring.

Physical: Spine, Knees. Back. Ankles.

Staying I love rather than simply loving.

Invisibility, being treated as an 'add on.'

Feeling you must cope/ mustn't let person you care for down.

Being constantly resourceful.

Advocacy for carers.

Follow up care plan with in 6 months.

Being a wife not just a carer.

Lack of connection, not complete rest at night, loneliness.

Physical stress, Backache, tiredness.

Professionals not 'listening/hearing' to what is being said.

Want to downsize home but too stressful for patient. Although would greatly help carer.

Anger, denial, grief and acceptance. Learning to care, revisiting bad feelings (back to square one), feeling you must do it all.

Emergency cover when carer is unable to care.

No emergency support.

Social life changes – one wants to go out, one doesn't. Need to 'hide' things/ rooms so patients not overwhelmed with anxiety or decisions.

Guilt at not being better informed.

Issues – Lack of (one point) information, Title 'carer' and resistance of person being cared for to accept this form of relationship (and tenor).

Recognition of carers by professionals.

Emotional stress, frustration, (Study shows can cause mental health problems.)

Being a good actor or actress.

Getting resources when you need them the most. I.e. when one is ill, the carer needs to do running around.

Exclusion from information and planning – particularly medical information.

Financial stress Cost of cover support very high part. During bank holidays £30 per hour!

CMHT staff need training in order to understand the carer's perspective.

'Its not an NHS problem, is it?' – Carers.

Physical stress of pushing wheelchairs – need teaching now!

Help people to help themselves – know support and back up is there if necessary.

Not enough information from doctors – should be able to be with patient at consultations.

Comprehension of the illness and the person's needs.

We should be given information directly as we would if visiting doctor with child. – We must know the score.

Quality support professionals don't listen frequently ignore carers.

Frustration at services non – recognition of family – support etc.

Sudden responsibility of caring, Entrapment – tied to the person you care for.

Care is more than doing tasks.

Men do care.

Not assuming that as one is a carer for one person, the carer will care for others.

Red Tape. Nobody coordinates support.

Coping, financial, social, health (my own).

Lack of communications – not told what I wanted to know.

Quality info, health, support, financial, work.

Professionals should not presume to judge the carer.

Frustration, lack of sleep, can't discuss decisions – shutters are down.

Training workers at every level why should I have to do this? (Continual change of worker!)

Having the illness by default.

Lack of training.

Change of attitude of officialdom away from “we know best what's good for you” LISTEN instead.

Professionals not understanding the difficulties faced by carers to make and keep appointments etc.

How to care for the recently bereaved – what happens after care?

Helplessness of not being able to take pain away, energy to help, time constraints

Financial stability, support to combat isolation from the first moment. Breaks – chance for rest & recuperation.

Finding info and support – where to look? – Is it legitimate to ask for help?

GP identification.

Limitations of 'therapeutic' intervention.

Need doctors to acknowledge the impact on carers' lives of other factors e.g. specialising other chronic illnesses cares as patients and vice versa.

One stop information.

Understanding.

Mental health – Planning a section so that a) Son would not run away beforehand b) Son would not hate me forever.

Recognition.

Challenge and keeping the helpers in order.

Individual voice.

Day to day emotional roller coaster of being carer. Physically demanding, emotionally demanding, guilt/frustration, own sense of loss of both individual you care for and own life.

How to maintain standards within the home and the options available- Moving, downsizing, convincing help is needed.

To deal with the system.

Insufficient info for handling side effects of medication. Finding way around NHS – no signs posts! Not being empowered.

Priorities – Do I care for the dying person or the carer?

Emotional pull and responsibility being sucked into a life that is not of your choosing. Misplaced respect for end of life care (at the expense of long – term carers).

Have to be eternally grateful, frustration, emotions, people won't go extra mile.

Putting one's health on the back burner!

Need for support: Practical, emotional, financial, training issues/practicality of patient's condition (funded replacement care).

The mental health carer should be an integral member of the CMH team. The 'Care coordinator should be legally obliged to include the carer in the loop.

Ineffective, multi- disciplinary, team working.

Challenges: Dealing with frustrations of achieving adequate support from local agencies, Balance of own personal needs and that of person being cared for, exhaustion, limited help available and more needed.

Support.

Carer's health.

Respite.

Listening to carers, reaching the NHS staff who are in direct patient contact, understanding carers need to be listened to and respected.

Finding time, Overcoming sense of isolation, physical demands of caring, handling complicated emotions – despair, guilt, love.

People in health service are marvellous, but the systems are crap – lumbering and with impenetrable care pathways.

Officialdom.

Mental- tiredness, patience, guilt, self control, confidence, lack of social life, living in a 'bubble.'

Hospital Discharge.

Not understanding the system.

Carer's dilemma: Do we make waves about something or will it have repercussions on care of relative or sour relationships with professionals?

Feeling afraid, who can we talk to? Looking after ones physical/ mental self, finding time.

Anger at the 'System' & helplessness at clinical and bureaucratic culture.

Involving carers in rehab programmes to meet their needs.

Collective voice.

Fear of expressing 'negative' thoughts difficulty of negotiating with NHS and its professionals.

Physical tiredness, red tape-dealing with social services etc, organising the day, self denial.

Feeling need to address injustice, empathy with those wronged by system.

Isolation, being cut off from the outside world.

Presumption that because one cares for one family member, one is automatically the carer for another family member, which is NOT necessarily the case!

Not being included in the patient/care relationship with GP, confidentiality of information.

Accessing care for patient at times of personal illness/crisis for the carer. Often easiest way is to continue to do the job oneself even despite ill health etc.

Minefield of benefit systems, no respite.