Building Effective Home and Family Care-Giving
Communication, Collaboration, Coordination

BY GRÁINNE SMITH
INTRODUCTION

Whether someone has a long-term physical condition (i.e. multiple sclerosis; arthritis) or a mental health problem (i.e. Alzheimer’s; schizophrenia) or perhaps a mix of both (i.e. eating disorder; alcohol addiction), family and other home care-givers often mention similar queries and problems: the lack of relevant information about the illness or condition, and difficulties in finding the right resources and support. These queries and problems add greatly to the personal stress, often over long periods of time, which affects the everyday life and health of care-givers themselves; as illustrated by the following quotes:

“Trying to be a carer is like trying to do a jigsaw blindfolded. There are always some of the pieces missing. I don’t know how long I can keep going.”
– John L.

“The hardest thing is that she’s just not the same person, the Maggie I knew has gone. It’s like a bereavement but you can’t grieve – it’s not like when my dad died.”
– Sandra B.

“I just don’t know what to do – why won’t anyone tell me how to help my daughter, what to do and what not to do? I don’t want confidential info about Jay’s condition but I do need to know how best to support and help her. When she became ill I’d heard the words ‘anorexia’ and ‘bulimia’ – but had no idea of what they meant. All I knew was that people died from anorexia. I worry endlessly about doing the wrong thing and making things even worse for her.”
– Gráinne Smith

Every care-giving situation is individual and different – yet there are many echoes of similar feelings. It is now being recognised that to create the best care possible for any vulnerable individual, it is essential not only to build excellent inpatient care but also the most effective home care possible, ensuring that – whatever the illness or condition – home carers know how best to support and care for their loved ones in very difficult times at home. This entails building good all-round communication to coordinate all care efforts for the vulnerable person. Without such essential communication and collaboration, the person requiring care may go from a very sheltered setting with professionals to a home environment where people in the household may have no idea of what to do to help, let alone how to offer that essential support.
No matter how much home carers want to help, without relevant information to inform their efforts, it is extremely difficult to build the best 24-hour care possible. Care giving at home is extremely demanding on the care-giver too: it involves emotional as well as physical support; administering prescribed medications at the right times throughout the day; organising a household (i.e. cooking, shopping, cleaning, taking care of finances, etc.).

WHO IS A CARER?

When someone is born with a health condition major or minor, or a health condition develops slowly over some time, or suddenly as the result of an accident, the person or people they live with are known as carers – or as home or informal care-givers. These carers may be of any age – from very young children to long-retired older people – and they may also be supporting the household financially.

Anyone can become physically, emotionally or mentally unwell, suddenly or over a space of time, and the person or people they live with then become home care-givers. There is rarely any time for preparation and reorganisation of a home situation, let alone any training. Home carers are simply expected to cope with the new circumstances, sometimes long-term.

The vulnerable person at the centre will have care through health and social services – perhaps an appointment every week, every month or less frequently. Apart from these appointments – possibly lasting only a few minutes – the person needing care usually spends most or all of their time at home with their ‘home carers’, sometimes a single person struggling to cope with massive life changes.

To build the best 24/7 care possible, the home team need relevant information and good communication to build good care. In other words, it is necessary to establish good teamwork between professionals, between all household members, and between the vulnerable person and everyone involved in the essential care giving efforts. A very tall order indeed!

FINDING RELEVANT INFORMATION AND RESOURCES

Often health centres and GP surgeries can offer leaflets about various health conditions – some may even know of a relevant self-help group. Another avenue to try is through relevant charities and voluntary groups such as Beat UK, Marie Curie Cancer Care, Carers UK, etc. Look for a relevant phone number: the main office of an organisation may be able to suggest a contact for a local self-help group in your area.

Also, try checking your local paper for information about charities and possible contacts in your
area. For instance, NEEDS (North East Eating Disorders Support) Scotland was started, developed and organised over several years by carers and people recovering from an eating disorder. The group now meets once a month, offering help, support, and information. People who attend can share difficulties, in confidence, with others struggling with these conditions.

Most charities have been started by one or two individuals who have personal experience. So, if you can't find what you need in your own area, perhaps ask to put a notice up in your local community centre or GP surgery or library and try to find a few other people in a similar situation to meet up with and share information.

BUILDING GOOD HOME COMMUNICATION AND TEAMWORK

Every home is individual, and every member of the household is an individual with different perspectives, attitudes, feelings and ways of expressing those feelings. Every day in the life of each individual is different. With so many individual viewpoints, feelings, attitudes and information, building good all-round 24-hour communication and collaborative care is not easy!

Daily life is made up of many minor incidents as well as some major and important incidents. Whatever the incident, communication can make or break the situation. Major incidents can be tackled in a practical way, whilst sometimes a minor incident can be blown up out of all proportion. Therefore, whatever the condition or the circumstances, it is extremely important for the home care team to work out the best way to help the vulnerable individual at the centre.

A Few Pointers

• Listening skills are very important. Personal patience (or not), awareness of body language, relevant information, generosity of spirit, no assumptions about what someone really means are all essential yet extremely difficult as they are often affected by tiredness plus other distractions or worries.

• Even in the best of circumstances, misunderstandings can happen. Therefore, it is really important for any group to share time together to discuss any important situation. People tend to have very different routines in any given day or week which makes finding time when they can all be together to try to resolve any awkward situation affecting everyone in the household all the more important.

• Getting everyone together gives everyone an opportunity to talk about what they have observed/been conscious of, and how they feel about changes in home life.

Family Meeting: Preparation

• Agree a good time when all household members are free and suggest everyone thinks about the changed home situation and makes a note of their concerns – any observations they’d like to make, anything they feel particularly affects them, behaviour they find difficult, etc.

• Ask everyone to think what incidents have affected them, how they feel about what’s happened, how it affects them and others. And what they find helpful and supportive.

Often health centres and GP surgeries can offer leaflets about various health conditions – some may even know of a relevant self-help group.
• Agree beforehand when the get-together will finish so that no-one misses an activity they specially enjoy.
• Who will lead the meeting? A parent or grandparent? A special friend or neighbour? A supportive professional? It might be a good idea to take it in turns.

Family Meeting: Rules

To make sure everyone has an opportunity to talk, discuss and agree on some basic rules. In my opinion, these should be 3 golden rules of every meeting:
• No mobile phones, tablets, games or other distractions. Discuss why the welfare and well-being of family members are much more important than any game or distraction.
• Suggest an agreed maximum time for any one person to talk. Designating a ‘time-keeper’ who can choose a signal that time’s up is always a good idea.
• One voice at a time. No interruptions when someone is talking. Remind everyone that their own turn will come.

Family Meeting: Topics for Discussion

A blackboard or sheet of paper displayed at home where family and other home team members can note items for discussion can be very useful in working out all the topics to be dealt with as well as giving everyone time to think about the topic to be discussed and what they want to say.

Family Meeting: Tackling Difficult Topics

When no agreement is reached after much discussion of a single issue, it can help to suggest coming back to that topic later, or suggest it be discussed at a future round-the-table talk when everyone has had more time to think through the issue and possible solutions.

Important Observations

• Living with any individual means sharing accommodation. Home team members are often the first to notice physical or emotional problems. However, they often don’t realise what particular signs may be significant. When emotions become tangled due to life events, or perhaps distorted by mental illness, challenging behaviour can cause major difficulties for everyone in the household. And most people find it difficult to know how best to respond when these signs begin to cause difficulty in the household. Keep reviewing the situation: often a pattern can be recognised and an ‘Early Warning Plan’ can be established. Sometimes, in long-term conditions, a relapse may even be avoided. This is where a family meeting can be very helpful, not only in sharing observations and co-ordinating efforts to support the vulnerable individual, but also in providing support for other family members.
• Breaking long-standing though often unwritten basic family rules can often signal personal distress. These observations can be really important, yet without relevant information it’s often difficult to decide what to do to help.
• Personal confidentiality is extremely important. Many carers have tried to obtain information from a GP and have found out that due to confidentiality for adult patients no response can be given. In this situation, rather than trying to phone or speak directly to the GP, writing a
letter outlining your concerns and quoting specific incidents may be a valuable addition to the information the GP already has.

Useful Phrases

In our busy world it often seems difficult to notice what is happening in other people’s lives – unless something adverse happens which directly affects us. Often when someone is unwell their self-confidence and self-esteem can be badly affected, their view of the world and everyone in it can be skewed, all of which can lead to difficult behaviour.

Sometimes time can pass quietly until that peaceful time is shattered by, for instance, someone using an unfortunate wrong word or phrase which can trigger an adverse reaction from someone else.

To avoid triggering difficult reactions and making the situation worse, working out what you want to say and how and when to say it, is extremely important. These are a few suggestions:

- I feel very concerned you often sound angry about…….
- I feel upset when you…….
- Can you tell me why you……?
- I’d like to help you…….
- I’d like to understand why you…….
- Can you explain……?
- I love you very much…….
- I find it difficult to see you in distress…….

Of course, it is easy to say these words when rehearsing and not so easy when under pressure! Try to remember:

No blame, no judgment, no attack. Emphasise that you are trying to understand the troubled person, and if possible you are willing to help.

Motivation

Every situation, every condition or illness is different depending on the health, personality, character, background and life experiences of the individual. Therefore, it is important to try to work out how best to support that particular individual towards making positive change in whatever difficult situation they’re in.

These are a few general suggestions to work towards positive change:

- Be as warm and caring as possible.
- Let them explain their arguments for change/not wanting change.
- Focus on their concerns.
- Stress choice and responsibility.
- Be prepared to talk about your own role as care admitting your own mistakes – this often encourages others to acknowledge their own.
CARER SURVIVAL

Family and other home carers give many hours of caring for people they love and feel devoted to, for as long as that daily care is needed – which can be weeks, months and years, sometimes even decades. Long-term care-giving can be exhausting, frustrating, sometimes even frightening – and can lead to exhaustion and health problems for the carer.

Some carers become so focussed on their efforts to offer the very best individual care possible that they seem to forget that their own health and well-being needs to be considered too. Unless they too have time to ensure a good diet for themselves as well as others, time to relax and enjoy their own favourite pastimes, visit friends, find and enjoy hobbies, perhaps join an interesting class or club, the result could be exhaustion and even collapse. Taking care of yourself as well as your loved one is not a luxury, it is essential! Without respite and time to relax, carers risk lowering their own resistance to infection, as well as feeling exhausted, isolated and depressed.

Make a list of all the things you’d really like to do – i.e. time to yourself to relax and read, to listen to music, to be with friends, etc. Then choose one item on your list and think about what steps you need to make it happen. If you cannot see how, try contacting a friend or a relevant charity/centre near you to offer guidance. A doctor or social worker or local authority may also be able to give you information about respite care in your local area. In the UK there are now statutory rights for people who provide long-term care at home.

Keeping a Journal

Isolation is a common feeling in a care-giving situation. Writing down or drawing (or a mix of both) how you feel about daily happenings and problems can often be a great outlet. Remember, spelling and grammar don’t matter in this work. So, just go ahead and write how you feel however you want to express it. Afterwards you might want to keep what you’ve written; or perhaps develop it as a story which happened to someone else; or perhaps even decide that your memories are so horrid and painful that a ceremonial shredding is the only way to find relief.

CONCLUSION

Remember that each home situation is different. Look for what you feel is needed to support all your home care-giving efforts and explore how to find what you need in your own situation and circumstances.

If you’ve enjoyed this white paper, you might want to consider purchasing a copy of my Routledge book – which covers all of these issues and a lot more in great depth:


For more information on this title, please visit: http://goo.gl/e6ok2J