

## 10. MAKING YOURSELF HEARD

Asking for help isn't always easy, especially when we all like to be independent and feel we should be able to cope. But always remember that, as a carer, you are saving the taxpayer thousands of pounds by the care you provide. You have the right to be heard.

Be prepared to try-out the help offered, even if at a later date you decide it's not for you. When family and friends ask if they can help, tell them clearly about the best ways they can help. They may *really* not be sure about what they could do.

Discuss with the person you care for what kinds of support you both need. It could be:

- Information or advice - practical, financial, emotional
- Practical help with medication, personal care or transport
- Equipment
- Regular breaks

You won't always get all the help you need, or receive it straight away, but at least if you know what you want, you can start asking and feel more in control.

Remember your needs may be different from those of the person you care for. You might like a break, but they are reluctant. Try to involve someone else in explaining your needs, possibly a relative or friend, a doctor or nurse. You may have to learn to assert your needs more forcefully, even if you feel guilty about it. Remember if you are not there to care, the alternative could be a residential or nursing home full-time.

### The System...

Many carers feel powerless and also undervalued by professionals. They feel that their knowledge and skills are

ignored and that they are not seen as part of the caring team. Nevertheless, it is important that you make yourself heard and that you are able to deal with a system that is often not as organised as it should or could be!

Some people are very approachable, some are not. So you need to build up your confidence. Some of the following ways could help:

- Think of situations where you have been successful: taking something back to a shop, sorting out a school problem. Focus on all the skills and knowledge you **do** have.
- Talk to other carers who are also dealing with professionals.
- Before meetings or phone calls, write down the main points and practise what you want to say.
- Be specific and concentrate on the main points; don't let yourself be side tracked. Try to avoid being confrontational, but be firm and calm. You don't need to be apologetic about contacting them. That's what they're there for!
- Remember that professionals may also get frustrated by lack of resources and time. They may not realise that you have a need, if you don't tell them. If you say you are coping and that all is well, they will probably believe you!

### Making a complaint

Sometimes things go wrong and you may need to make a complaint. It could be about the level or standard of the service or about the behaviour of an individual. Sometimes you can sort things out informally by talking to the person concerned, but not always.

It is important to complain as soon as possible after the event. If you wait too long, you may lose your right to complain and

certainly it always becomes more difficult to remember the details of what happened. It is helpful to make written notes as soon as possible after the event, as a record.

If possible, put your complaint in writing and keep a copy. Make a record of phone calls - who you spoke to; the date; what was said and what was agreed. Health, *Adult & Community Services* and the Local Authority are required by law to have written complaints procedures, which you can ask for. Independent agencies and homes, as well as voluntary organisations, will also have complaints policies.

If you have a complaint about your doctor, contact the Practice Manager. If you are not happy with the reply, you can contact the Complaints Officer at the appropriate Primary Care Trust (PCT). Similarly, you should contact the PCT for complaints about your pharmacist, dentist, optician or Community Hospital if you can't resolve your problem with that service. Complaints about the Acute Hospitals should go to the Chief Executive, or you can discuss it with the Complaints Officer of the appropriate hospital. Alternatively, you might find it helpful to contact your local *PALS*, *Patient Services* or *PoHWER/ICAS*. These can advise you and/or take up the matter on your behalf. The *Citizens Advice Bureau*, *Worcestershire Association of Carers*, *DIAL* and *Age Concern* can also help support you.

### **Patient Advice and Liaison Service (PALS) & Patient Services (formally PALS)**

This is a service offered by the *NHS* to provide 'on the spot' information about the *NHS* and to help you with any other health-related enquiries. It can also help you resolve concerns or problems you have when using health services and can provide information about the *NHS* complaints procedure and how to get independent help should you decide you want to

make a complaint. If your concern is with GP's or community health services you can contact **PALS** but if it is to do with the Acute Trust i.e. the hospital services, you will need to contact **Patient Services**. (the numbers are in the list of contacts)

### **Independent Complaints Advocacy Service (PoHWER/ICAS)**

If you are unhappy about the treatment or level of service you have received from the *NHS*, please ask to speak to the person in charge of the area, department or ward to try to resolve your complaint. Alternatively, you may wish to use the *PoWHER Independent Complaints Advocacy Service (PoWHER/ICAS)*. This is an independent service that can help you make a formal complaint. *PoWHER/ICAS* provides support, help, advice and advocacy from experienced advisors and caseworkers.

You can also write to managers of organisations, your local councillor, MP or the local government ombudsman.

### **Advocacy**

If you feel you need support in order to speak out, to help to defend your rights, or need someone else to act on your behalf, you can ask an Advocacy Service to support you. The role of advocates is to:

- enable you to have your voice heard or made known to others
- ensure you are treated fairly
- enable you to have access to information and be aware of choices available to you
- provide training for you to develop skills to be able to advocate for yourself in the future.

Advocacy services are particularly funded to provide a service for carers.

## **Comments and compliments**

Most services receive complaints. If things have gone well, feedback is also useful to know where they have got it right. Thoughts about how minor improvements could make a big difference are also helpful. Either contact the service to let them know your compliments/suggestions or ask them how to make a formal comment and compliment on the service you have received. PALS is a way of passing on your positive and negative experiences of your local NHS, so that services can be improved for everyone.

### **Remember:**

- **You should not be penalised or branded a troublemaker because you complain.**
- **All complaints should be treated in the utmost confidence by the organisations concerned.**
- **By making a complaint, you may also be helping others who are having the same problem.**