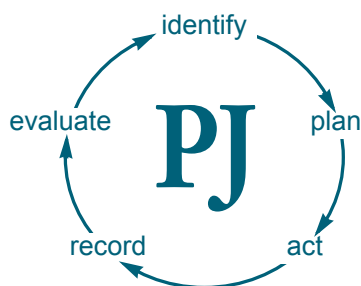


HOW PHARMACISTS CAN SUPPORT CARERS

By Felicity Smith, PhD, MRPharmS, Sally-Anne Francis, PhD, MRPharmS, and Nicola Gray, PhD, MRPharmS

This article describes the range of medication-related activities that are undertaken by carers together with some examples of the types of problems that they experience. This background may assist pharmacists in developing services to support carers in their medicines management roles and thus contribute to Government policy as outlined in its strategy for carers



identify gaps in your knowledge

1. Who are carers, and what medicines-management activities do they undertake on behalf of, or in partnership with their care-recipient?
2. How can carers be helped with the problems they experience in relation to their medicines-management activities?
3. What general support is available to carers?

This article relates to the Royal Pharmaceutical Society's community and hospital competencies of "the needs of both patients and carers" and "the needs of special groups in the community" respectively (see "Medicines, ethics and practice — a guide for pharmacists", number 26, July 2002, pp105–6). You should consider how it will be of value to your practice.

The term "carer" is now used to refer to people who, in the past, were called "informal carers". Carers are defined as people who look after or provide some regular help for a sick, handicapped or elderly person living in their own or another household and who are unpaid. In the United Kingdom it has been estimated that there are 5.7 million carers, one living in every sixth household. Carers include people of all ages and the person they care for (the care-recipient) may be an older relative, a sick child or younger adult, a neighbour or a friend.

In the UK, carers have been estimated to save the state £57.4bn each year.¹ The important contribution of carers has been recognised by the British Government, which published a national strategy for carers in 1999.² This document acknowledged the significant role of carers and the need for improved information and support services for them. The national service frameworks for mental health (standard 6) and older people (standard 7) also target caring about carers.

Caring for a person can range from buying the weekly groceries to giving more personal care such as helping with bathing and dressing. Researchers have found that responsibility for medication is often an integral part of the caring role and that carers undertake a wide range of medication-related activities, all of which have their associated problems.^{3,4} Also, one-fifth of people aged over 70 years have been found to receive assistance with their medication.⁵

WHO IS A CARER?

In developing support for carers, the first problem for pharmacists may be identifying who they are. People providing assistance to others will often not see themselves as carers: they are just being husbands, wives, parents, children, friends or neighbours, even though the help they provide may be vital to the well-being of the care-recipient.

Since problems have been shown to be associated with all types of medication-related activity, in designing a service sensitive to the needs of carers it is important that pharmacists are able to identify all people among their clients who may potentially benefit. A first step in identifying carers may be to ask people collecting medicines from the pharmacy on behalf of others about their medication-related activities. By being proactive in identifying individuals who may require assistance, it avoids the problem of people not identifying themselves as carers. Awareness can also be raised by displaying posters and leaflets.

MEDICATION-RELATED ACTIVITIES UNDERTAKEN BY CARERS

The level of involvement of carers in medicines management activities varies immensely. However, it has been shown that carers who have what appears to be only minimal involvement may experience considerable problems in performing these roles. For example, a carer whose role only consists of collecting the care-recipient's medicines from the pharmacy could have difficulty if a query arises over the prescription. The carer may not be able to help with the query and therefore can experience delays collecting the medicines. These people may also be less likely to already be in regular contact with health professionals than those providing intensive support.

The medication-related activities undertaken by carers can be categorised into three main roles. The examples given in this article are from structured interviews that were conducted as part of recent research into the roles of carers when managing medicines for older care-recipients.^{3,4} Some of the problems discussed here might be solved when Government schemes like the electronic transfer of prescriptions are put in place but, until then, pharmacists need to be able to help carers overcome these problems in an acceptable way.

Maintaining continuous supplies of medicines Maintaining supplies of medicines includes ordering and collecting prescriptions from the surgery, taking them to the pharmacy and collecting the medicines. These activities appear straightforward and routine, but can involve the more complex task of carefully monitoring supplies in the care-recipient's home.

As one carer explained: "She doesn't need all the tablets every time so I have to go through and see how many she's got left because the packets are different sizes. I only want this one, this one and this one, she'll say, and then the next occasion it's some of the others, it's a different amount. And to me that is a little complex. So it's specifying which tablets are needed, then two days later, because it takes two days for the doctor to write the prescription, to return and collect the prescription."

Dr Smith is a reader in the department of practice and policy, school of pharmacy, University of London, Dr Francis is a lecturer in the department of practice and policy, school of pharmacy, University of London, and Dr Gray is a lecturer at the school of pharmaceutical sciences, University of Nottingham

Additional problems can result from the planning required when ordering the prescription (eg, ensuring that there is enough time for the surgery to issue a prescription before the patient runs out of medicines), errors in prescriptions (eg, when computers are not updated), delays in issuing prescriptions and different pack sizes from the pharmacy, such that the need for further supplies of different products do not coincide. Furthermore, carers often take responsibility for ensuring that prescription details and supplies are correct. Transport to and from the surgery and pharmacy can also be a problem, especially for carers who have other commitments, such as a full-time job or a family. This burden is increased by the need for return visits to a surgery or pharmacy to check the accuracy of supplies or obtain the balance following incomplete supplies.

Instances in which prescriptions are sent directly from the surgery to the pharmacy, pharmacy collection and delivery services and the willingness to "lend" small supplies of medicines are valued by carers. However, in the context of wider developments in the provision of pharmacy services, developing support services for carers may be part of a framework of closer collaboration with local surgeries, and in some cases form part of a new system for management of repeat prescribing, supplementary prescribing and responsibilities for long-term medication. Closer liaison with surgeries can also facilitate the process of ordering of prescriptions, assisting carers in maintaining continuous supplies and ensuring that changes in therapy are identified and that carers are informed.

Generic substitution, which is widely practised, can lead to particular difficulties for carers. The following quote illustrates how this can create a problem for a carer in the context of the partnership between carer and care-recipient in medicines management activities: "One of the biggest problems is [that] she recognises the tablets. She scrutinises everything. So if I get [medicines made by] a different manufacturer from the pharmacy, although it may be the same chemical constituents, if it's not the same manufacturer, I have the whole problem of trying to explain to her 'now, this is the right tablet'. She knows it has got this colour foil and this writing on the back, and if it doesn't look the same, then she is not going to take it."

For some carers, interventions such as attention to the most suitable packaging, clear and informative labelling, and the provision of advice, especially in the supply of generic products for which a change in the appearance of products may lead to concern, would reduce many difficulties.

Assisting with administration Assisting with administration can present practical difficulties as well as being stressful for carers. Many carers themselves (especially if older) may have difficulty with containers or packaging, remembering doses and managing particular formulations. Being available throughout the day to assist with the administration of complex and frequent dosing regimens can be difficult and burdensome. The following quotes provide examples of the kind of practical assistance that carers provide and illustrate the stress that can be associated with these activities:

"So all I do, she's got a bottle there, and I do about half a dozen for her, just split them in half, they break badly. So what I've got is a small Stanley knife, I do half a dozen for her."

"Sometimes it's a case of fetching the medicine; constant reminders 'Have you taken it?' Dopamine, of course, you probably know, needs to be taken regularly; we're on a two-hour cycle at the moment. We set alarms to go off at the appropriate hour, which we don't like very much, we're tired of the noise."

Discussions with carers could focus on the identification of practical and other assistance given in the home and how this can be supported. For example, use of suitable containers when a carer has difficulty. In some cases it may also be appropriate to consider how medication regimens may be modified so that they are more easily accommodated alongside the carer's other commitments. For example, a slow release preparation could be prescribed where appropriate.

Clinical roles Many carers will have a detailed understanding of their care-recipient's condition and be aware of the impact of medication. Thus, they may continually make judgements regarding the appropriateness of prescribed medication and carefully monitor the impact of any changes.

Although it is important for pharmacists to ensure that carers (as

well as care-recipients) are able to make appropriate decisions regarding medicines prescribed to be used "as required", decisions about the timing and adjustment of doses are not confined to these types of medicines. Carers also worry about, and make adjustments to, doses of medicines prescribed for regular use. Concerns include over-dosing, under-dosing, determining the correct dose and polypharmacy. As one carer reported: "I have questioned with the doctor, and the pharmacist, especially when she came out of hospital, certain medication I didn't think she needed, and they agreed. Over prescribing in my opinion. She was on 23 tablets and nobody seemed concerned. It took two weeks to get them reviewed, and from 23 she went down to four."

Carers have also reported omitting doses and stopping medication altogether. A common reason for this is side effects, for example: "We were prescribed a quantity of phenytoin, and it made her so sleepy, I reduced the amount." Adjustments to doses and their timing may also be made to accommodate carers' own commitments, as well as the perceived needs of the care-recipient. For example, the timing of administration may depend on when the carer leaves for and comes back from work, rather than being regularly spaced throughout the day.

Awareness of the levels of clinical involvement of some carers is important in ensuring that the provision of information and advice is tailored to the carer's and care-recipient's needs and concerns. Although written information may be widely available, problems in interpreting this information and using it to inform judgements regarding the needs of individuals are well documented and pharmacists can play a valuable role here.

Assumptions cannot be made regarding adherence to medication regimens and it must be acknowledged that making clinical judgements is both an inevitable and sometimes a desirable aspect of the caring role. Carers need advice and support in these activities.

SENSITIVITY TO THE RELATIONSHIP BETWEEN THE CARER AND THE CARE-RECIPIENT

In developing services for carers, health care professionals must remember that medicines management activities will often be undertaken as a partnership between the carer and the care-recipient. In many cases they will work together, sharing information, views on appropriateness and responsibilities, and discussing their perspectives and activities. However, sometimes, their perspectives regarding, for example, the need for medication differ: "We do have problems, although I think I've got her now to agree that she needs to take them. At one time she was messing them about, she'd take them for a week and think 'Oh well, I'll have a week off'. But I think I've got through to her now that it is important with both of them that she takes them regularly. And that can be extremely irritating and long-winded at times — you feel you've said it over and over again."

Sensitivity to the relationship between carers and care-recipients is required. There may be a delicate balance regarding maintaining appropriate levels of confidentiality and protecting care-recipient autonomy and providing information that enables carers to be effective in their medicines-management roles. According to the Royal Pharmaceutical Society's Code of Ethics and Standards, pharmacists and their staff are expected to keep any information concerning both the prescribed and non-prescribed medication of an individual confidential. Such information may only be disclosed to carers with the care-recipient's consent, or without consent if the age or health of the care-recipient makes them incapable of consent. However, in practice, strictly maintaining this standard presents difficulties.

Medication-related problems and the concerns of carers must be evaluated in the context of the care-recipient's needs and the relationship between them. This may include an awareness of how responsibilities are shared, so that carers receive the information and advice that they need while any wishes of the care-recipient to retain autonomy and confidentiality are not forgotten. Despite having to rely on others for medicines management activities, care-recipients can put great emphasis on the need to retain their independence and privacy regarding information about themselves and their health. The patterns of partnership, and consequently the desire for confidentiality and autonomy, may differ greatly between, for example, an older couple living together, both of

PANEL 1: HELPFUL ORGANISATIONS FOR CARERS

- Carers UK carers line provides free advice and information to carers 0808 808 7777 (helpline)
- Princess Royal Carers Trust provides, information, hardship grants and travel assistance www.carers.org 020 7480 7788
- Contact-a-family (for families with disabled children) www.cafamily.org.uk 0808 808 3555 (helpline)
- Counsel and care (help and advice for older people and their carers) www.counselandcare.org.uk 0845 300 7585 (advice line)
- Age concern (for older people) www.ace.org.uk 0800 009966 (information line)
- Sane (for people with mental health problems and their carers) www.sane.org.uk 0845 767 8000 (helpline)
- Crossroads (provides short term breaks to carers in their own homes) www.crossroads.org.uk 0845 450 0350

whom may have medication-related needs, and a parent caring for a child who may gradually assume greater responsibility for their medicines themselves. There will also be a need for continual review as the caring role is dynamic, in that the needs of the care-recipient, and the ability of the carer to cope, may increase or decrease over time.

GENERAL SUPPORT

Apart from supporting carers in medicines management, pharmacists should be aware of other needs of carers. Caring for another person can place the carer under both physical and emotional strain. Some carers may find themselves suffering from problems such as sleeplessness, backache or depression. Often, pharmacists are the only health care professional that carers have regular contact with and simply remembering to ask how the carer is when handing out the care recipient's medicines can make a difference.

Many carers give up employment to care for the care-recipient and can find themselves feeling isolated, as well as financially worse off. Pharmacists can help by acting as signposts, pointing out helpful organisations such as Carers UK. Panel 1 provides a list of useful contacts. A general awareness of the kinds of benefits available is also useful because many carers assume that they are not entitled to any help. If a care-recipient has needed help for three months because of a severe physical or mental illness or disability, and he or she is likely to need help for at least another six months, a disability living allowance (DLA) may be claimed. This is not affected by savings. For people with a terminal illness, there is a system in place to help them get DLA more quickly. In addition, if a carer spends at least 35 hours each week looking after a care-recipient who is receiving or waiting to hear about benefits such as DLA, he or she may be entitled to a carer's allowance. Claimants should be aware, however, that many benefits are interdependent and claiming one allowance may affect entitlement to another. Details are available from the Department for Work and Pensions (www.dwp.gov.uk) or local social security offices. Information leaflets on topics such as getting the most from primary care, how to get help, how to prepare for someone coming out of hospital and benefits are available free to carers from Carers UK.

CONCLUSION

Identifying people who provide assistance to others, many of whom may have limited involvement and would not describe themselves as carers, but nevertheless may benefit from a service for carers is an essential step in the development of such a service. Services must be tailored to the individual needs of carers and care-recipients and be feasible in the context of delivery of care in the pharmacy.

Developing these services provides opportunities for pharmacy

action : practice points

1. Carers week runs from 9–15 June. It aims to raise awareness of carers and carers' charities. Run an event in your pharmacy to promote awareness of carers and work out how you could devise a system for the identification of carers who come to your pharmacy and may benefit from support regarding medicines management activities.
2. Based on the range of activities and examples of problems experienced by carers, consider how you could develop a protocol that will be workable in the pharmacy and enable you to find out more about the activities that carers that come to your pharmacy undertake, the problems they experience and how you may support them.
3. Maintain a record of any actions taken in response to the needs of carers so that the service can be recognised and reviewed.

evaluate

How could your learning have been more effective?
What will you do now and how will this be achieved?

which are in line with new directions in the wider development of professional services and current health policy initiatives. As pharmacists assume increased responsibility for the repeat prescribing process, supplementary prescribing and overseeing the needs of people taking medicines long-term, there will be even greater opportunities to develop services which address carers' needs and reduce the burden associated with their medicines management activities.

REFERENCES

1. Carers UK. Without us? Recalculating the value of carers support. London: Carers UK; 2002.
2. Department of Health. Caring for carers: a national strategy for carers. London: Department of Health; 1999.
3. Francis S-A, Smith FJ, Gray NJ, Gaffry J. The role of informal carers in the management of medication for older care-recipients. *Int J Pharm Pract* 2002;10:1–9.
4. Smith FJ, Francis S-A, Gray N, Denham M, Gaffry J. A multicentre survey among informal carers who manage medication for older care-recipients: problems experienced and development of services. *Health Soc Care Comm* 2003;11:138–45.
5. Jones D, Vetter N. Formal and informal support received by carers of elderly dependants. *BMJ* 1985;291: 643–5.