
Supporting dementia workers

A case study-based manager's guide to good practice in learning and development for social care workers supporting people with dementia

Spring 2012

“we help create
a trained and
qualified workforce”



Preface

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Acknowledgements

Guilt is common for carers who find they become irritable with the person's odd behaviour or constant questions, or resentful at feeling forced into a role they did not choose.

Uncertainty. Life is unpredictable and no two days are the same. Despite meticulous planning, unexpected things happen and the carer has to cope with frustrations and disappointment. There is fear over the future. Will I be able to keep going? How will I cope with the later stages of the dementia?

Evolving feelings. Initially there is the shock of adjusting to changes; as one carer puts it, in the early days she was in denial and unwilling to acknowledge there was a serious problem and "our anxieties banged up against each other and raised the temperature." Sometimes there is a phase where the person with dementia accuses the carer of hurtful things. Eventually the carer may face the pain of not being recognised by this person - perhaps who has been their life partner.

Feeling trapped. The person with dementia may feel anxious if the carer is out of sight, so may follow them around the house. Carers are not free to come and go as they please, to pursue hobbies or see friends. Even simple tasks like shopping or attending medical appointments can be difficult. There are few breaks from the 24 hour responsibility. Short breaks to pursue interests or friendships can seem costly to the carer which might deter the caring from seeking opportunities to go out.

Conflicting demands. Work and other relationships suffer. Left with inner conflict and resentment, they neglect their own needs. This is especially true where the person has young onset dementia and there are children living at home still.

Feeling lonely and isolated

Often the carer has lost their closest supportive relationship because that person is the one with dementia. The parent or partner can no longer show concern for the carer or give the support they have relied on over many years. Carers struggle to shoulder all the responsibility and decision-making which was previously shared.

Other networks of friendship also diminish. The carer may have given up their job because of their caring role. Friends and relatives may stop visiting because they find the situation difficult. Sometimes the carer's decisions are questioned by friends and family members who don't see the full extent of the difficulties posed by the dementia; it can be deeply painful to face criticism for doing what you believe is in the person's best interests. It can also be difficult to go out because of financial constraints and anxiety over how others will respond to unusual behaviour.

Carers often feel they are the only one going through this experience, that no one understands. Sometimes personal dignity or not wanting to be pitied can cause carers to 'put up a front' as someone who copes.

Practical demands of caring and the risk of exhaustion

Caring for a person with dementia has many elements. Emotional support and reassurance for the person are key at all stages, but early on the carer has also to take on many practical tasks such as looking after the house and garden, shopping, and taking care of finances. As the dementia progresses, more care is needed. The carer's role goes from prompting and reminding to giving more and more help with eating, washing, dressing and going to the toilet. Extra effort needed to maintain communication can be very tiring. As one carer put it, "Much of my energy was spent trying to interpret him to the world, and the world to him."

In the later stages, mobility, continence and swallowing difficulties can lead to the person needing a great deal of help with personal care, as well as extra washing and food preparation. There may be anxiety over the health and safety of the person with dementia, the pressure of continually needing to assess risk, living in a constant state of high alert. Often, this is happening at a stage of the carer's life when energy levels are lower.

The physical demands might be manageable if sleep were guaranteed, but many carers have broken nights because dementia disrupts their relative's sleep patterns, perhaps resulting in anxious or obsessive behaviour during the night. For carers who don't live with the person with dementia, there may be the stress of continual 'phone calls at all hours of the day and night and the carer rarely feeling relaxed. Finally, financial pressures are common for carers who may have lost employment and face extra costs caused by the dementia.

Feeling ill-equipped and unsupported

Most carers feel unprepared to take on this new role. How can you feel confident as a carer if you lack the basic information about dementia that will help you understand what is happening and how to respond? At the point of diagnosis many carers are not in a position to absorb information they are being given about dementia symptoms, strategies that can help and local sources of support.

Many carers struggle to accept help. They may feel they should be the one providing all the care and no one can care for the person as well as them. Or the person with dementia might be against involving anyone beyond the family. Other family members may dislike the perceived stigma of needing outside help.

Wanting to care

Despite the pressures, there is a desire to care and a motivation to do the best for the person with dementia. Satisfactions of caring vary from carer to carer, but common themes include wanting to repay the kindness received over many years from the one who now needs support, and the opportunity to be close to the person and protect them. Those who support families can acknowledge this desire to care and help maintain the rewards caring brings.

What do carers need from care workers?

Some key points for workers supporting the carers of people with dementia.

Respect the carer as an equal partner with you. They know the person with dementia best and have discovered strategies that work. People working in social care should work corroboratively to find the best solutions.

Listen to the carer and find out how they are coping. Recognise that the carer may say they are 'fine' and appear cheerful while underneath they are struggling. Pick up on stress signals through questioning and observation.

Remind the carer that they have needs too. Encourage them to take time to rest and relax. If they are struggling to accept breaks, help them see benefits that might come for them and the person they are caring for. Be knowledgeable about the help available and share this information.

Be sensitive to difference and don't make assumptions. Not all relationships are the same. What is the nature of the relationship between the carer and person with dementia? Be aware of how differences (of race, religion, sexuality) are relevant to the caring situation. Even simple things, like forms of address you use, can show your understanding of cultural differences.

Recognise the reasons a carer may be abrupt or impatient. We make allowances for the person with dementia, but we also need to recognise the strain carers are under which might occasionally make them a little less polite than normal. Carers have to be insistent at times to achieve the best for the person for whom they are caring; their role includes being an advocate.

Avoid being judgemental. Each carer finds their own way of coping within their limitations.

Be flexible and open to exploring alternative solutions. Thinking creatively leads to better outcomes for a person with dementia and their carer.

Use appropriate communication methods.

Many carers are not online, so emails are not a good way to reach them. Mobile phone conversations can be difficult too if you catch the carer in a public situation and try to address confidential care matters; ask the carer if it is a good time to talk.

What carers of people with dementia look for in social care workers:

Knowledge and experience of dementia and available resources.

Good communication and listening skills.

Ability to be flexible and proactive.

Ability to share ideas and co-operate with the carer.

Good time-keeping and reliability.

Ability to detect triggers, likes and dislikes, in a person with dementia.

References

Alzheimer's Society (2012) *Dementia 2012: A National Care Strategy*.

Moise, Schwarzinger and Um (2004) *Dementia in the 21st Century: A Global Perspective*, OECD Health Working Paper no. 13, OECD: Paris

Getting to know the person with dementia and their family

In order to care for the person with dementia, you need to understand them, and the carer is usually the one who knows them best—they are the expert on that person. As well as meeting with the carer, you could ask them to write down things that will help you; from likes and dislikes, care needs and health issues, through to biographical details and interests. This will enable you to tailor the support you give, acknowledging how much the person can do independently and seeing what help

Carer's perspective: "On the day I first took my husband to the day centre, we were greeted immediately with a warm welcome. The workers always made sure my husband was happily absorbed in some enjoyable activity when I was ready to take my leave. At one stage, things became rather difficult and my husband was reluctant to leave home with me to go to the day centre. Fortunately they had a most understanding outreach worker, and when I phoned to explain the position, she drove over to our flat and persuaded him to come with her to the centre. I appreciated the flexibility, initiative, imagination and willingness to literally 'go the extra mile'."

While the person is with you at the day centre, you might be able to provide aspects of care that are difficult for the carer at home, such as helping them have a bath, a shave, or a haircut. What happens during the time at the day centre can either help or hinder the carer. If you help the person experience wellbeing and retain abilities, this will have a positive impact when they get home. If the person is frustrated or over-stimulated, the carer might be left picking up the pieces. Give plenty of warning should there be plans to discharge a person from the day centre; it will be a great shock and a huge loss if it is done suddenly without warning. Carers need to make other plans.

Showing sensitivity

It is important to be aware of how the carer and the person with dementia wish to be addressed and respecting this is particularly important if the family is from a minority ethnic culture where social etiquette is different. Be especially tactful when telling the carer about any problems, or the carer can feel they are being blamed. Remember that the scindfui oblem, and

Carer's perspective: I'd received a phone call from me my husband's day centre, asking me to help with another carer who had been spilled in the home the was weakening.

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Transport matters

The journey to the day centre is an important part of the experience of attending a day centre. Transport staff need to know how to respond to people with dementia, using skill in gently coaxing a person who is reluctant to get on the bus and helping them feel settled during the journey. It will also help if they keep the carer informed of when they are hoping to arrive and if they are delayed.

Key tips for day centre staff

Value and use the carer's knowledge of the person with dementia.

Recognise and respond to the carer's feelings of anxiety.

Communicate regularly and meaningfully with carers.

Help carers feel part of the service by inviting them to occasional events.

Be sensitive to the carer's feelings in working through any problems.

Be punctual in collecting and returning the person with dementia.

Carer's perspective: "If only the home carers would take their shoes off when they come in. I don't like to ask them because they might think I'm being fussy and take it out on my wife, but the stains on the carpet are really getting me down."

Carer's perspective: "She came bustling in and turned the radio off. It had taken me ages to settle Dad with the soft music he likes so much. The home carer said it was boring, but Dad soon got restless when he couldn't hear the music."

Being a friend

Carer's perspective: "A young man who was studying law gave my husband personal care at home over quite a long period, so we got to know each other well. He always managed to raise our spirits when he arrived at the at, and he would give me reassurance and encouragement if I seemed distressed, always with a smile and sensible words. When the time came for my husband to go into the care home, this kind young man knew how upset I was about it, and made special arrangements with his agency to alter his schedule so he could accompany us in the ambulance to the home, helping him down the stairs and providing cheerful company all the way. I will never forget him."

Although you have to work within professional boundaries, in time you will become a familiar face, and the carer may look forward to seeing you, as one of the few people they speak to on a regular basis. Remember to look out for signs of when they are struggling and the situation is deteriorating. It will be easier for the carer to accept your help if they feel the relationship you are building enhances their relative's life. Carers want domiciliary workers to show warmth and engage their person with dementia in conversation as they are providing care. For example, the photographs you may see around you can provide an opportunity to ask and talk about grandchildren and the

extended family and support the discussion of the life story of the person with dementia.

Carer's perspective: "I like it when people who come into our home talk to my husband and listen to what he is saying, or trying to express, even if it seems inappropriate or rude. Above all, I want them to enjoy the time they spend with him."

Teamwork

Remembering carers who don't live with the person with dementia

Not all carers live in the same household as the person they look after. This is especially true for sons and daughters caring for parents. They might live in the same town or a considerable distance away, but they are providing a lot of support and need to be informed of the domiciliary worker's visits. This might be through 'phone calls, emails or text messages. Using a communication book in the person's home might help in some situations, though there is a risk the person with dementia will tidy it away or be confused or distressed by what is written. Talk to the carer about how best to keep in touch with them, as each person will have their own preferences.

Top tips for domiciliary care workers supporting people with dementia

Find out as much as you can before you visit, so you are prepared.

Treat the home as you would want a visitor to treat your home.

Build a supportive, respectful relationship with the carer.

Notice anything that is changing, including the carer seeming stressed.

Find ways to complement the carer's role and make their life easier.

Don't forget the needs of carers who live in a different household.

4 Personal assistants

Personal assistants (PAs), or people employed directly by people with dementia and their carers, usually work in the home of the person with dementia, so many of the principles from chapter 3 apply equally to this role.

Respecting the home, and learning about relationships between the people who live there, are necessary skills for personal assistants as well as domiciliary care workers. But personal assistants work in a different way to enable the carer in their role supporting the person with dementia.

Carer's perspective: "Our PA was vary varied in terms of what they did. He went along to reminiscence sessions, took my husband to the tip to get rid of rubbish from the garden, helped walk the dog, cut the lawn, or supervised any of these activities if my husband was having a good day. The reason he made such a difference is, even a trip to the local tip reminded my husband he could still do normal things, which in turn increased his self esteem. Because he has known my husband as long as I have, the memories they share go back many years.

"This allowed me to relax, knowing that my husband was safe and entertained. The personal assistant also filled in a 'day sheet' which told me on arriving home where they'd been that day, what they had done, what my husband had for lunch, anything that had upset him, if he had slept at all, how noisy or quiet the day had been for them..."

Being flexible

The job of personal assistant is broader than most roles in social care, because it encompasses whatever is needed to support people with dementia to live as they want to. Rather than undertaking a limited set of tasks, such as helping with personal care or eating, the personal assistant might also help the person maintain interests and friendships, go on holiday, look after pets, go shopping or attend appointments. They need to be versatile and creative over how they use their time, and flexible over availability.

Another key difference from other social care roles is that, under personal budgets and direct payments, or through private arrangements, the personal assistant is employed directly. In the case of people with dementia, the family carer is usually the employer, responsible for defining the role and providing necessary training and employment safeguards. A further distinction

is that many personal assistants work with just one person, or possibly with a small number of people with dementia. They spend longer periods of time with the individual(s) and are able to get to know them well. This depth of knowledge about the person, and sensitivity to varying moods and abilities, enables the personal assistant to adapt to the needs of the person they are supporting.

You will be most effective when you discuss with the carer how your contribution will best fit around the carer's role, so that you work as a team to achieve quality of life for the person with dementia. It is important to clarify the carer's expectations, offer suggestions and give constant feedback on what has worked well and any difficulties. Discover biographical information to help you plan activities, and share your ideas with the carer who is ideally placed to advise.

Doing practical tasks can help the person with dementia to feel you are there for practical reasons and may reduce their feeling that they are being 'minded', which might cause some frustration in the first few days of the role.

A carer's perspective reported : "The PA soon learned that part of the role the carer wanted her to fulfil was to act as advocate. When Mavis was out visitors sometimes called at an inconvenient time, such as when Ron (the person with dementia) was resting, having a meal or receiving personal care. With Mavis's permission, the PA would tactfully ask the visitor to return at a more suitable time."

Keeping up-to-date with best practice and linking with local groups

When you work for an organisation, they are responsible for making sure you have the right training for the job. If you are a personal assistant, the carer might send you on training, but you may also have to be proactive in finding suitable courses and other ways of learning. In particular, you will need to find out about dementia:

- how best to respond
- person-centred approaches
- progression of dementia
- extra prompting and support

This will help the carer feel confident in your capacity to support their relative in the right way. A good place to seek advice for relevant training is your local authority or from Skills for Care (www.skillsforcare.org.uk).

You might also benefit from linking in with local organisations that support people with dementia. They might offer courses or be able to advise and support you, and they might also run groups, outings and other social opportunities for people with dementia in which you could help the person you are supporting participate. You will meet other people who are in caring roles

Top tips for personal assistants

Keep as your focus helping the person with dementia live their life.

Be a reliable, trustworthy presence for the family.

Find ways to update your knowledge and skills in dementia care.

Link in to local social and support networks.

Be flexible and creative over how you spend your time.

Share your ideas with the carer and listen to their advice.

Give the carer a summary of the time you have spent with their relative.



24-hour service to which they can turn, even in the middle of the night.

Carer's perspective: "The worker was extremely enthusiastic, supportive and passionate about the carers' support group. I felt part of a small family, nurtured and understood. I gained insight, information and most importantly was not judged for my lack of knowledge and seeking tips from those who had been caring longer than me."

Making time to listen

One of the ways we can most help carers of people with dementia is by being a good listener. Carers sense that voluntary organisations have time for them as an individual. The carer can talk through their feelings and questions in detail, and this is a real safety valve. Because the focus is on listening to the carer, voluntary organisations are good at responding flexibly with services that meet their needs; innovating, filling gaps and doing things in ways that reflect their local community. Think about ways your organisation's volunteer befrienders, listeners, or counselling service could be offered to people with dementia and their carers.

Providing information, training and advice

Local voluntary organisations for carers often provide opportunities to learn about aspects of the caring role, such as back care and first aid. Particularly in the early months after a diagnosis, carers value opportunities to find out how dementia affects the brain and changes they might see in their relative. Written information about dementia and details of services that are available can also be a great help. Voluntary organisations are more able to be clear about rights and entitlements than

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Key tips for voluntary organisation staff

Be a friend and an advocate, helping the carer access help.

Provide opportunities for friendship and socialising.

Cultivate listening skills and make time to listen.

Help resource carers through information and education.

Find ways to support the carer—simple things that make them feel special.

Who are standards for?

Dementia 2012: A National Care Strategy, published by the Alzheimer's Society, March 2012.

Living with Dementia: A National Dementia Strategy, published by the Department of Health, February 2009.



6 Local authority workers in carer support roles

Carer's perspective: "Two years ago, when I was caring for my mother who had dementia, I took up the role of carer co-chair of our local authority's Carers' Partnership Board. The board is a forum for carers to be involved in decision-making and influencing change. I have also been part of a scrutiny panel, looking at what services are available for carers within the borough and their accessibility, identifying gaps and how these can be met, and turning rhetoric into reality. We obtained funding for a 'hub' at one of the libraries where carers can access information, help and activities from other organisations. Recently carers were invited to be part of a presentation on

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Providing support

Some local authorities run support groups for carers of people with dementia. This provides

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8 Social workers, care managers & self-directed support practitioners

Carer's perspective: "My main problem was my mum's lack of awareness of her condition and resistance to acknowledge she needed help. The referral to the social worker was a turning point. She visited Mum alongside the health visitor and played it sensitively and tactfully. As I live 100 miles away from mum, I was never able to meet [the social worker] in person, but she said I was welcome to call or email her at any time. Several times she spoke to me on the phone for about an hour. Of all the professionals, I felt she had the most insight into behaviour in dementia. It was she who told me that I needed to be looking at residential care, as Mum was getting to the point where she was not safe to be at home alone. I knew this myself, but was in huge emotional turmoil and felt paralysed by this."

Social workers, care managers and self-directed support practitioners all have unique support roles for people with dementia and their carers. Some suggestions and perspectives from carers to support partnership working are given here.

Feeling your way into the situation

Tact and diplomacy are more vital than ever when visiting families where dementia is the cause of care needs. Whereas in other caring relationships the person receiving care accepts they have needs, with dementia it is hard to explain to the person why social services are involved; people with dementia often lack the insight and cognitive ability to grasp the impact of their changing needs on family members. Spending time listening and observing will help you gain a feel for what is happening in the home and where the pressures points lie. This includes hearing the perspective of the person with dementia and involving them in all conversations about their care, but it may also entail picking up the slightly different messages the carer wants to give about how they are managing and coping.

Carer's perspective: "Mum needs help with everything. I visit to bring her food, fill the fridge, do the washing, clean the house, but she told the care manager that she does everything. The care manager looked in the fridge, found it full, and concluded she did not need any help. If the care manager had told me when she was visiting, I would have been there to explain how things really are."

Being knowledgeable about dementia and services that can help

Carer's perspective: "The most important thing for social workers is the ability to listen and then explain things clearly. I found it really confusing to be given different advice about the notice period when asking for respite provision. It varied between three weeks and eight weeks, depending on who I spoke to. It was extremely stressful on one occasion when I gave six weeks respite. I found it really confusing to be given different advice about the notice period when asking for respite provision. It varied between three weeks and eight weeks, depending on who I spoke to. It was extremely stressful on one occasion when I gave six weeks respite."

In order to give the best possible help and advice to support people with dementia, carers suggest that knowledge and skills in two key areas are vital:

Understanding dementia – understanding grows through experience, but it will also be important to keep your knowledge up-to-date in the usual ways. Ideas about best practice are developing constantly and ongoing research refreshes our ideas about what will help.

Understanding the role of benefits and services – by keeping in touch with provision in your area by networking and by visiting local services, you will be well placed to make suggestions that match the need at each stage in the dementia journey. The carer will rely on you to give accurate, up-to-date information. It may be worth attending courses on legal and financial matters relevant to working with people with dementia.

Being introduced to the world of social care can be bewildering and you can help by using clear explanations and plain English to describe sources of help. Some carers prefer concrete examples of support available, others find it helpful being asked general questions about 'What would help you?' A short tailored list of organisations may be appreciated by a carer who is feeling bewildered by the sheer volume of information available.

Using a problem-solving approach

You may find yourself employing new tactics for introducing support if the person with dementia cannot accept they have needs, and that their carer needs support. Conventional approaches may meet with resistance, so introducing new people slowly and building support gradually may be necessary. You might have to work with the person with dementia, helping them understand their carer needs a rest, before they agree to try out a new day centre, for example.

Another aspect of supporting families of people with dementia is that the situation rarely stays the same for more than a few weeks. Dementia is progressive, so you will need to explain to the carer how to keep social services informed of changes so that support going in to the home is adjusted regularly. Carers feel anxious when they are discharged after support packages are put in place, unsure who to contact in a crisis. need to know who to contact if they have a problem with any of the agencies supporting them, and to feel sure that the problem will be resolved quickly.

Carer's perspective: "When the care manager sets up support from a care agency, there must be a constant flow of communication, and prompt actions when changes are needed. When there was a dispute or non availability of care services from the agency, I wanted the care manager not to be biased but to look at the facts of the matter and respond fairly and not in favour of the care agency."

Helping the carer see their needs

The needs of the person with dementia tend to be the focus of everyone involved with a family, from friends and relatives to health and social care professionals. The spotlight is rarely on the carer, and how their life has changed. One of the key ways you can support carers is by helping them see the needs they have too, and encouraging them to accept help. This involves acknowledging and valuing their central role in supporting the person with dementia, and

Approved mental health professional (AMHP) roles

Some roles in relation to people with dementia are exclusively reserved for social workers who are AMHPs. If you are working with this client group, you will require training and support in implementing protocol and local procedures in these specialist areas in particular their behalf are in their best interests. It is important to note that suitably trained and warranted nurses,

Being efficient

Leading well means being organised, thinking ahead and having good systems. Keeping carers informed and involved is essential when supporting people with dementia, and will require careful planning and excellent communication. If there are changes in the way the service is run, carers need to be informed as soon as possible. You can delegate these tasks to team leaders, but check they are keeping up with the responsibilities. A simple thing, like replying quickly to emails and other communication, gives the carer confidence and minimises the likelihood of frustration. Being proactive in involving relatives also reduces the risk of problems escalating and resulting in a formal complaint.

Carer's perspective: "The manager of my mum's care home is always on the ball and responds quickly to any queries. When I emailed her about a blocked toilet in Mum's room, she responded immediately and had maintenance deal with it as a priority. She wrote to families recently to explain a fee raise, in a way I felt was clear and responsible. And she seems to take care of staff welfare and morale, so you generally feel that it is a happy place for them to work and for the residents to live. This, I think, is down to firm, clear leadership and good communication."

Key tips for social care managers in provider settings

Be a role model for staff in communicating well with carers.

Support staff and ensure they are well trained.

Keep up-to-date with best practice in dementia care.

Network with other managers of dementia care services.

Be open to comments and criticisms from carers and act on them.

Develop good systems for involving and communicating with carers.

Give regular updates about the service and staffing matters.

10 Conclusion

A carer's perspective reported: Edna refused to let the domiciliary care worker do anything for her, and it was getting to be a real problem for her husband who desperately needed support. So the care manager thought long and hard about what might be causing this problem. She wondered if Edna might be thinking something was going on between the domiciliary care worker and her husband and suggested that when the worker came, the husband took the opportunity to go out and buy his newspaper. This worked a treat—Iris was pleasant and obliging with the care worker when her husband was not there. It took imagination and empathy to solve the problem.

Some key suggestions as to how you can work more effectively with the carers of people with dementia:

Think yourself into the carer's situation

Think how life would change if someone close to you developed dementia. Understand how the carer must feel when they can no longer carry on with the life they had been used to. Each time you have contact with the carer, imagine what might have happened already that day to contribute to stress and tiredness, and remember to ask how they are.

Be positive and imaginative when thinking about providing support

Try not to say that something the carer suggests or requests is not possible, but figure out ways you could make it work for the family. Be creative and adopt a problem-solving approach to help overcome obstacles by offering original and individual responses. Be optimistic, not focusing on the negatives but seizing the potential for wellbeing in dementia and encouraging the carer to hold on to roles and relationships which maintain their own identity.

Treat the carer and the person with dementia with friendship, dignity and respect

Always remember that it is what you bring as a person to the relationship with the family that makes the biggest contribution. Building mutual

11 Further reading from Skills for Care

This is one of four related publications all free from the 'Developing skills' > 'Dementia' page of www.skillsforcare.org.uk The others are:

Caring for people with dementia: a guide for carers
Dementia: a guide for carers
Dementia: a guide for carers
Dementia: a guide for carers

See also the Dementia UK site, www.dementiauk.org



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