Tips for home carers with a migration background

1. The care puzzle

Home care by family and friends demands a level of commitment that is very difficult to predict when it comes to the amount of time it takes and the length of time it will last. Sometimes on a daily basis, sometimes on a weekly basis, you constantly need to put together the pieces of a puzzle that takes account of yourself as the care provider, your care recipient and all the other people around both of you who have anything to do in any way with your mutual care relationship.

This is by no means an easy task.

You may think that organizing your time and the things you need to do is not a 'task'. But you would be wrong. It is probably the most difficult task of all! This making of the time puzzle is a direct consequence of your commitment as a home care provider. In other words, the time you spend putting together the time puzzle - making all the arrangements that are necessary to make all the pieces of the puzzle fit - is also time that you need to take into account. But how do you do this? And who do you show your puzzle once it is ready? Who is a priority partner when it comes to time? How do you draw up a common time plan for the other carers who share with you the same care provision?

What do you need to take into account when making your care puzzle?

• Make a list of all the tasks that people expect from you as a care provider. It is important to do this in as much detail as possible. The more task tasks you identify and the clearer they become, the easier it is to combine these tasks with your own personal agenda and the agendas of the other home carers who share the care provision with you. An example:

Preparing medication. This is easy, if you know what's needed. But this seemingly simple task involves a number of other tasks:

Who follows up any changes in medication?

Who arranges new prescriptions with the doctor?

Who goes to the chemist?

- Estimate the time needed for each task. Every task takes time. Using your experience, you should be able to estimate this quite accurately. This can be important in a later stage if it becomes necessary to delegate tasks; in other words, hand tasks over to other people who can share the home care provision with you. If people know exactly how much time a task is going to take, they will find it easier to agree to it.
- Note the starting time and finishing time of each task. If the care recipient has an appointment with a doctor, specialist, physiotherapist, etc., you will need to provide transport there and back and also wait while the appointment takes place. Sometimes you can use that waiting time for other care tasks, but not always. Waiting time is also task time.
- Work out when the task can be fitted into your agenda. You don't have to do all the tasks
 by yourself. Perhaps you can delegate some of the tasks to other people. If so, you need to
 identify these tasks clearly.

- Calculate the average amount of time you use each day, week and month to carry out your care tasks. It can happen that some days or weeks you have very few care tasks to perform, whereas at other times you will almost have too much to do. What is the likely time structure of the home care provision in which you are involved?
- Take account of your work time, if you have a paid job. Try to get a clear idea of your working hours (each day, week and month, if you can) and see how this fits in with your care commitments. For people with variable working hours, this can be difficult. Even so, it is something you need to remember when making your care puzzle.
- Take account of how much time you need for your own family. Life in your own home doesn't stop just because you have agreed to provide home care for a relative, friend or someone in the neighbourhood. So what are you going to do for the care recipient and when? Who can take your place if you are not available? Are there special events coming up at home that are going to demand more of your time: the Sugar Festival, a birth, a wedding in the family, a return visit to you homeland, getting a new house ready, etc.
- See if anyone can help you to provide the home care. Perhaps you can delegate tasks to other people. Perhaps there is someone who can take your place at short notice if you are too busy or held up. Perhaps there is some professional hep available. Perhaps there are day care facilities for your care recipient. You need to explore the possibilities to give yourself a breather. This is also time you need to take into account.
- Last but not least: me time and free time. Make sure that you keep some time for yourself! You can't devote yourself 24 hours a day to your care recipient. You'll never keep it up!

- * Tasks and their intensity can vary over time. This means it is a good idea to have another look at your care puzzle every once in a while. Is it still accurate? Are there any problem tasks and problem moments? How can these be solved? Home care is a constant factor that you need to take into account in your life, but the how, where and when are less constant. Re-examining your care puzzle once every six months is not excessive.
- * Prevention is better than cure! Don't make your care puzzle when things are hectic or difficult. Do it when things are quiet and calm. See what needs to change and look again at the overall picture.
- * Make use of the available digital tools. The use of a smartphone, iPad, computer, etc. is now common. Sharing digital agendas, warning each other by a text message if something has changed or in emergency situations: these are things that can save a lot of time and prevent misunderstandings. It helps you to avoid an overflowing e-mail inbox and all those long telephone calls where you have to explain the same thing over and over again. In the end, contacts of this kind, especially if you are at work, can be very tiring and do not help you at all. It is important to keep on investing time in learning how to make best use of these digital tools. Making payments by iPhone is transparent, simple and something you can do during 'dead' waiting hours: anytime and anywhere.

2. Take good care of yourself! Self-care is not a luxury!

Sometimes it will seem like there is no end to the questions of your care recipient. Sometimes the demands of family and friends are equally high. A lot of people talk about what you do, but very few do much to help you in practical terms. Providing home care is by no means self-evident and not always easy. Take some time for yourself. Otherwise, you will never keep it up.

Working tips: 'me' time

- Make sure you have some 'me' time in your planning and treat it as sacred. Dare to set limits! If your 'me' time means you need to find a bridging solution for your care provision, arrange this well in advance.
- Dare to speak in 'I' messages. Being assertive is not a question of being difficult, but is about
 making clear agreements about what you can and can't do. Making promises you can't keep
 doesn't work and only breeds distrust. Clear communication with your care recipient, your
 own family, your relatives and your friends shows the limit of your commitment within the
 boundaries you have set.
- Dare to ask for help with your care provision. Sometimes just asking people to help, concretely and directly, is enough. People are often afraid to ask if they can do something, because they assume that you always do everything, and that's the way you like it. Learn how to talk to people about these things. Learn how to take a step back and sometimes leave things for others. In this way, you will be able to delegate some tasks and make more opportunities for your 'me' time.
- Have complete trust in the people with whom you share your care provision. Whoever agrees to perform a care task is the owner of that task. Keep your distance and don't interfere with the way the other carer carries out the task. For example, if three of you share the daily task of providing a warm meal for the care recipient, don't always be checking up to see how the other two do it. Don't compare. Don't judge. Anyone who takes on a care task must always make sure that someone can act as a replacement if something intervenes.
- Want to or have to? Sometime home carers have grown up in different places with different views about the world, different ideas about 'what can' and 'what must'. Traditional roles can sometimes persist: the eldest daughter, the good mother, the tireless employee... Does it have to be this way? Can it be some other way? Can it be arranged more simply? Can others help?

Working tips: respite

- If you feel the need to take a break from your care task, explore in advance **the possibilities for respite care** in your (immediate) surroundings. Don't wait until things become too much for you, so that you then need to find a solution in double-quick time.
- If your care recipient is taken into hospital, use the time to have a good rest. You don't need to be in the hospital from morning until night! Sometimes the recipient won't be in his or her room (tests, physio, operation, etc). Don't waste time sitting in an empty room!
- **Don't make yourself irreplaceable as a carer.** Make sure that you can fall back on the help of others, when needed. Because your life may be totally different tomorrow. After all, you can have an accident or fall ill, just like anyone else. And what then?

Working tips: coping

- Try to look at the situation realistically. Don't give yourself or the care recipient false hope. Don't cling on to illusions. For example, if the care recipient enters the terminal phase of an illness, you must accept that he/she is going to die and try to give that acceptance a place in your care relationship. Thinking about what is coming helps when the moment arrives.
- Try to gain more insight into the illness or condition of your care recipient. Ask about how the illness or condition will progress. Learn to recognize the different phases. Ask for explanation from professional carers, general practitioners, nurses, self-help groups, etc. This avoids needless irritation.
- Not all care recipients are easy and/or grateful. Sometimes they lack insight into their own illness or condition; sometimes they react angrily against their steady decline; sometimes they are frustrated by having no prospects for future improvement. They can express this anger and frustration in different ways: outbursts of bad temper, not saying anything for days on end, ignoring everything the carer does to make things as comfortable as possible for them. Sometimes they are grateful, but don't always know how to show it. Search for and value these signs of gratitude, even if they are sometimes curiously expressed.
- Let your feelings out! Talk with family or friends. Find a soundboard, someone you can confide in. It doesn't have to be another care provider. In fact, it is better to find someone who is not involved in your care provision, someone who can listen to your story from a distance. This will help you to better order your thoughts and feelings, and put them in a proper perspective.
- Look for contact with people in the same situation. Although each care relationship is unique, you can always learn from the experiences of people who are going through the same thing. Contact with other home care providers can help clarify matters, remove feelings of guilt, and chase away the gloom that all carers feel from time to time. Ask other carers and your general practitioner for more information.
- Avoid perfectionism. There is no such thing as perfection. The perfect home carer does not exist. You can learn from your mistakes, and what you don't know, you can ask. And don't be frightened to ask. You are a full partner in the care situation, so don't be afraid to join in discussions about what the care involves and how it will develop.
- Maintain good contact with professional carers. Get to know the other carers who are
 involved in the care of your care recipient. Good contact not only breeds mutual trust, but
 also leads to better insight and a better exchange of information. This takes time. Don't be
 impatient. Getting to know each other is a two-way process that won't happen in a single
 day.
- **Don't forget to laugh**. Humour doesn't always seem appropriate in a care situation, but it can help to lighten the atmosphere and put things in perspective. Your care recipient might have a totally different philosophy of life and view of the world than you do. This can sometimes be irritating, even frustrating. But always try to see the funny side in your differences.

3. Home carers with a job

If you have a job that take you out of your home, you are not always able to arrange your time as you would like. This can make things more difficult. And your work also takes up part of your energy. That's obvious! It also means that home care providers with a job need to think extra carefully about their care puzzle.

- Look carefully at your care puzzle, not only in the short term, but also in the medium and long term. If you are worried by the current intensity of the care programme, how long can you keep this up? Is the situation likely to change in future? For better or for worse? How will the care recipient's condition develop? Is professional support discussable? Are there people who will back you up?
- Make time for discussion within your own family. Reduced working hours, taking care leave, etc.: these are important decisions. What are the financial implications? Will this have consequences for the personal budget of every member of your family? Will your family be able to meet all its financial obligations both now and in the future? You need to take account of things like possible structural alterations to your house or the care recipient's house (for example, a stair lift), your partner's job security (or lack of it), children who will later want to go to college or university, etc.
- How important is your job in your life? Do you have career plans? Even though it shouldn't happen, it is often the case that asking for reduced working hours can damage your career. If you opt for time credit, care leave or reduced hours, are you going to devote all that extra free time to your care recipient? Or have you long had the idea of taking a time-out from your work, because you need a break or want to do other things?
- Talk to others and try to get information unofficially. The more you know, the more chance you will make the right decision. Don't do anything hasty. Explore your situation at work but try at first to do it informally. Do you know other colleagues who are home carers? How do they combine their job and their care tasks? Looking back, do they now think they made the right decision? The people you work with are a source of emotional and practical support.
- Talk to others and try to get information officially. If you never talk about your home care commitment when you are at work, it will be difficult for your colleagues and your bosses to know just how hard it can sometimes be for you. So talk to your personnel manager! Perhaps you will be pleasantly surprised by what is possible.
- How home care-friendly is your employer? Is there a possibility to make a flexible arrangement that suits your personal circumstances? Or must everything go through formal procedures and channels (personnel department, union representatives, management, etc.)?
- Assess the long-term effects. The decisions you take today may have consequences for the
 future. Time credit and care leave may be interesting options for the short term, but both are
 limited in duration. So what are you going to do in the longer term? And what about your
 social rights? If you opt for reduced hours, will this affect your right to certain benefits
 (unemployment, children's allowance, etc.)? And what about your pension? Will it stay the
 same or will it be reduced. Make sure you know before you make your decision. It will save
 you from unpleasant surprises later on.

4. Live-in home carers

As a home carer, do you live in the same house as the care recipient? Are you the husband, wife, mother, father, daughter or daughter-in-law of a father- or mother-in-law who is living with you?

Working tips

- If possible, make use of any available help services: day-care centres, short-term residential centres, small-scale specialist centres (for people suffering from a particular illness, etc.). This will give you some extra breathing space at home, to do the things you need to do at a slower pace or perhaps invite some friends around for coffee, etc.
- Make sure you have a place in the house that is just for you. A place where you can go if things get difficult. A place where you can relax, read, meditate, phone a friend, or use social media to contact your family, both to chat and to keep them up to date with the situation.
- Don't make the care recipient the central figure in the house. The care recipient must accept that he/she shares a living space with others. Living together is not always easy and it is everyone's responsibility to make it work. Equality in diversity is the key. The care situation is important, but as far as possible life in the house must go on as normal. The care recipient must be involved in household life, but must not dominate it. If the kids want to watch a different TV programme, don't always immediately say no. Make clear agreements about such matters. Each generation has its own culture and way of doing things. This does not mean there is a lack of love or respect. It's just how things are. Always and everywhere.

5. Home carers who do not live in the house of the care recipient

- Make sure you stay a member of your own family! Don't focus 100% on your care recipient. Obviously, you will talk about your care work at home, but not to the exclusion of everything else. Life goes on and your own family also have their own needs that you should attend to. If you fail to recognize this, your balance is not right. Home care outside the home must not be used as an excuse for never being there. If this is the case, you really have a different kind of problem...
- Communicate about your care planning. Let other family members know what your tasks are, so they know when you will not be at home and why. Failure to explain will lead to irritation, suspicion and lack of understanding. Nobody needs this unnecessary extra stress!
- Find moments when your family can also participate in your care activities. The more your family meet your care recipient and see where he/she lives, the more understanding and appreciation they will have for what you do. If the care recipient is a member of the family a grandparent, for example that will happen automatically. But if the recipient is, say, a neighbour or friend, it can help to get your family involved in the care process, whenever this is possible. In this way, they will build up their own bond with the care recipient and perhaps show more understanding at moments when your care activities take up a lot of your time.

6. Hospital admission

Care recipients often need to go into hospital, especially if they are old. A hospital is like a strange new planet, with its own rules and regulations. People often assume that hospitals in Belgium are the same as hospitals in their own country. This is not always the case. They are efficient, bureaucratic, high-tech, clinical and fast. As a result, the home care provider sometimes feels left out of things.

Working-tips for the admission of your care recipient to a hospital

- Ask for information from your general practitioner. The doctor is the best person to let you know what is happening, why, how long it will last and what the likely outcome will be. Note down whatever he/she says to you. Ask if there are clear multi-lingual websites where you can get more information. The more you know and remember, the less stress you will have later on.
- Most hospitals have an admissions booklet. This contains lots of information about registering on arrival, hospital insurance, visiting hours, possible overnight stays for home carers, etc. If the hospital admission was planned rather than an emergency, you can read all this information at your leisure in advance.
- Ask for a **translator** if neither you nor the care recipient understands the local language. In some hospitals this service is possible.
- If there is no admissions booklet, ask for information from the hospital's **social services** unit or in the department where your care recipient will be staying.
- If your care recipient has made a living will (about the medical treatment they don't want), let the hospital know. If a trustee has been appointed for this will, tell the hospital who they are and how they can be contacted.
- Inform the home care services to put those services on hold. Also inform the neighbours and the general practitioner that your care recipient is going into hospital (if they don't already know).

Working-tips for the discharge of your care recipient from hospital

- Make your preparations for receiving your care recipient back at home in good time.
- Ask regularly about the likely duration of the hospital stay and the likely date of discharge.
 In our experience, too many hospitals keep this kind of information to themselves and only
 tell patients (and carers) that they can go home a day (or sometimes even hours) in advance.
 This makes it difficult for the carer to arrange everything in time: warn the local care services,
 get the house ready, adjust their own planning, etc.
- Try to be present at the final discharge conversation in the hospital when your care recipient is ready to go home. In this way, you will know what you need to know about his/her current medical condition. Take plenty of time for this conversation and use a translator, if needed.
- During the discharge conversation, ask how things are likely to develop in the future. Don't
 be afraid to ask questions about possible changes in medication, the need for home help,
 necessary adjustments to the care recipient's home (stair lift, walk-in shower), etc. If the
 care recipient's medical condition means that he/she can no longer stay at his/her current
 home, contact the social housing agency to see what can be arranged.
- During the discharge conversation, ask about the administrative/financial arrangements.

• Inform all the local home care services as soon as you can that your care recipient is returning home. Tell them about any changes in medication, frequency of care, etc.

Working tips for the organization of home care following the care recipient's discharge from hospital

- As the main home carer, it is a good idea if you take the initiative to arrange all aspects of the home care once your care recipient leaves hospital. The hospital's social service unit will help you.
- Sometimes, the **hospital will already start arranging home care** after they have spoken to the patient. **Try to be present** at this conversation, so that you know what is happening and can make the hospital aware of your own care puzzle.
- Try to ensure the continuity of the home care services. Where possible, use the same services and people who visited your care recipient before the hospital visit.
- Notify all home care services as soon as possible that the care recipient is returning home.
 Tell them about the necessary frequency and intensity of the different tasks. Inform them of any changes in the situation (medication, revalidation, diet, etc.), so that they can make their own puzzle.

Working-tips if your care recipient needs to be admitted into a residential care centre

- Home care provision has its limits. Often you will feel this but won't admit it, because you don't want to let your care recipient down. Sometimes, the care recipient will sense this and put you under added pressure, because they want to stay at home as long as possible. Even so, if the care becomes too difficult and too demanding, so that the quality of the care no longer gives the care recipient the care comfort he/she needs, the residential option needs to be discussed.
- **Don't ignore signals from professional carers**, like home nurses, the general practitioner, social services, etc. Don't cling stubbornly to the idea that 'your' home care is the best solution for your care recipient. We repeat: home care provision has its limits.
- Regard the **signals from first-line actors as an outstretched hand**, as an extension of your home care effort. You must have the courage to discuss these things with the care recipient, with his/her closest family and with the professional carers.
- Regard admission to a residential care centre as a new phase in your care relationship with
 the care recipient. It does not mean the end. It is not goodbye. Many centres are happy to
 find a place and a role for the former home carers of their new residents. Your opinions and
 your continuing commitment will be valued. Make contact, make an appointment, express
 your wishes, and look for a way to play a new part in your care recipient's new life.

7. After the death of a care recipient

Even though you are rationally prepared for a care recipient's death, there is such a thing as 'the law of emotional inertia'. It takes time to process the death of someone close, time before you can once again use the experiences that have made you a richer person for the benefit of others.

Working-tips

- It may take some time before you recognize and accept that the person you are caring for is going to die. This is why it is important to **gain as much information as you can** about your care recipient's illness and the way it is likely to develop, particularly in the terminal phase.
- Home carers sometimes feel guilty. 'If only I'd done this..., if only I called the doctor yesterday..., if only I'd stayed longer this morning...' This is an understandable reaction, but wholly misplaced. Death is not your fault; you just need to give it a place.
- After the death of a care recipient, some home carers feel the need to remain in 'action mode'. If, as the care provider, you are given the chance to take part in the farewell ritual, this can often give you the time and the impetus to wind down from the 'care-alert' phase and move into a transitional phase that will help you come to terms with what has happened.
- **Grieving takes time**. Grieving is good and necessary. Grieving can sometimes be raw. But in time your grieving will change. What's more, there is no time limit on grieving. Missing someone or no longer missing them is not a linear process. It can come and go in phases, often associated with particular events (birthdays, last hospital admission, last meeting, last visit to family in the homeland, etc.) or objects (a photo you find in a draw, a favourite memento you were once given, etc.).
- If you were a home carer for someone who was not direct family, their death not only brings to an end an important relational contact and commitment in your life, but can also mean the loss of the context of that contact and commitment. You can no longer go into the care recipient's house, the family no longer seek contact with you, you have few tangible reminders of the years you shared together. In other words, some home carers experience a double loss: they lose the person and they also lose the environment surrounding that person.

The care relationship can often become much more intense during the final phase of the care recipient's life. This can mean that your care puzzle is even more heavily focused on your care commitment. What's more, this final phase can sometimes last a long time. This can make it a period with less 'me' time, less time for your family, less time for your friends. You do what you have to do for your care recipient. But afterwards, you need to wind down, you need to re-establish contact with your personal network. This also takes time and energy. Don't assume it will happen automatically.

8. Make sure there is good internal communication with the care recipient

By **internal communication** we mean the arrangements that you and the care recipient make together. To organize the care in a way that feels good for both sides, it is important to discuss openly and honestly. What are the needs? What are the underlying emotions? What are the different layers of the message? What are the signals you sometimes get that indicate without the needs for words that the situation is changing? Home care providers have, by definition, a personal and emotional bond with the care recipient and sometimes this does not make the internal communication any easier.

- **Empathize and stimulate**. The word 'emotion' is close to motion. If you empathize and reach out to someone, this has a stimulating effect. By identifying what emotions are present in your communication, you will be able to sense the direction you need to travel and what things can make the care recipient feel good.
- Use reasoned arguments. As a home carer, you cannot simply follow your emotions. You sometime have to tell things the way they really are or they way they appear to you at the time. This news is not always welcome to the care recipient, so you need to support what you say with reasoned arguments. Why is a home nurse now necessary? Why is a short-term break in a residential care centre a good idea? This is a form of communication with a rational basis, but you still need to express it with feeling and compassion. Experience with many carers has taught us that repetition is the key. Make your arguments, leave a pause, and then make your arguments again. Sometimes, it is necessary to let time do its work. If the situation evolves in the way you thought, time will be your ally. But keep making the same arguments and keep motivating the care recipient to move in your direction.
- Inspire. Keep your eyes and ears open. Sometimes you will discover new evolutions that can make your care provision easier or can enrich the life of your care recipient. Will the care recipient be able to communicate better with a touchscreen? Or better read the mails of grandchildren via social media? Or keep in contact with more distant relatives by Skype? Remember that you can only inspire others if you believe in what you propose. It is not a question of 'must', but things can change and many more things may be possible in the future than is now the case.

9. Make sure there is good external communication

By **external communication** we mean all channels, lines of communication and contacts that you have as a home care provider with outside agencies and other interested parties. This can include other members of the family, the professional care services, your own employer, etc. Precisely because home care in the unseen side of the care world, this kind of external communication is not always easy, self-evident or transparent. As a home carer, you sometimes need to find the right moment to 'break in' to another platform or line of communication.

- Make clear who is speaking and what you are speaking about. If you are speaking as a home carer with other (professional) carers, you need to start with a moment of 'clarification'. Who are you? On whose behalf are you speaking? Why are you calling? What exactly is your message? Sometimes, you need to do this in consultation with the care recipient. But sometimes things happen unexpectedly. For example, as a non-live-in home carer you might arrive at your care recipient's home one day and find that he/she has had a bad fall. At that moment, the need for communication with the professional care services is more important than consultation. Remember the four key 'W's': who, why, what and where.
- Find the shortest line of communication. What is the situation and who do you need to help you? If you get a worried telephone call from your care recipient because the home care nurse has not turned up, you need the contact details of the nurse as quickly as possible, so that you can contact him/her to find out what has happened. Getting upset and phoning all the care recipient's brothers and sisters to let off steam may make you temporarily feel better, but it doesn't really achieve anything.
- Communicate your message in a logical way. Always begin with the most important thing. What is the core of your message? What do you want to ask? Only then should you give less important subsidiary information. An example: you share the home care of your parents with your two sisters. Today you notice that your dad has the first symptoms of flu. You want to let your oldest sister know, because she is the main home carer. You send her a mail, because that is what you have agreed. Don't start your mail with all kinds of irrelevant news about the weather, your children, the cat, etc. Just say what you need to say about your dad and leave it at that. Perhaps even put the core message in your mail title. In this way, the mail will get your sister's attention more quickly.
- **Be discreet.** As an intensely committed home carer, you will get to learn a lot of things about your care recipient, perhaps even more than (other) close members of his/her family and the professional carers. Being discreet with this information is an essential form of respect. Don't gossip about your work as a home carer. Of course, using this information at the right time and in the right context can be a way to enhance or enrich the care trajectory of your care recipient but this is something very different from gossiping. Exchanging delicate information in this way is therefore acceptable, but keep it to an agreed small circle of people. It is better to tell these people what they need to know, rather than letting them find out by some other way. But Facebook posts and tweets about what you experience as a home carer... no, that's taking things too far.

- Act as though you are a full care partner. Don't be too shy or modest. Make sure you are
 present during important conversations about your care recipient. Say what you think, but
 don't force your opinions on others. In the final analysis, it is always the care recipient who
 decides. That being said, your knowledge about the context can be crucial in reaching the
 right decision.
- **Demand respect**. It is important to demand respect in a firm but friendly manner, both for yourself as a home carer and also for the choices that need to be made about your care recipient. Don't let yourself be put off or pushed into a corner not by the social services, nor by secretaries, doctors, etc. Nowadays, we are all busy, but a solution supported by all parties saves time and achieves the best results for everyone.
- Make contact with other home care providers. Each carer's story is different. This variation can sometimes offer inspiration for new solutions in your own situation.
- Talk in terms of 'I' messages. What works for you? What doesn't work? What are your experiences? What changes have you noticed? By using clear 'I' messages, you give yourself a clear place in the care environment. You are not just a 'doer'; you are involved in the care process as a complete person.
- Be aware of the channels of communication that are open to you. Who can you pour your heart out to? Who can you ask for advice about medical evolutions? Who can you consult about the different levels of intensity in home care? Who can you confide in when you need a break from your care duties? It is not necessary for everyone to know everything. But it is important that you know who you can contact when you need specific help or guidance. Perhaps you want to discuss with other family members the possibility of them playing a bigger role in the care scenario? The support of a professional carer can sometimes make your request seem more neutral.

10. Making financial arrangements

- Transparency is essential. If your home care commitment, which you do with your heart and soul, turns out to be more difficult and last longer than you first imagined, it is a good idea to discuss certain things and put them down on paper. What are your financial powers as the home carer? Perhaps you are trusted with full powers; perhaps the care recipient's professional carers or family member have joint powers with you and check all the bills; perhaps you have no financial powers at all. As a home carer, find a place for yourself within the context of the situation and have this confirmed, in writing if necessary, by others involved in the care process.
- Don't be afraid to make clear to others if the care situation changes. Even if you have no financial powers as a home carer, you can still signal to others that a changing care situation makes it necessary to look again at the financial aspects of that situation. A deterioration in the care recipient's condition, a hospital admission, a transfer to a residential care centre: keep everyone informed and tell them if you think this has financial implications.
- Good contact thanks to good contact procedures. As a home carer, you respond to an acute care need because the care recipient is known to you and you want to do something for

him/her. But this does not mean that you should 'sacrifice' yourself or suffer financial loss as a result. A good contact procedure involves the following elements:

- ° the name and address of everyone involved in the care process
- ° your commitment and responsibilities as the home carer
- ° the commitment and responsibilities of the care recipient
- ° the duration of the commitment
- ° the amount or method of calculating any payment due to the home carer
- ° how the payment is made.
- If you are promised something in a will, check this carefully and in good time. It can sometimes happen that the care recipient wants to reward the home carer by promising to leave them something in their will. What is the value of such promises? And how can you check if they have done anything concrete about it? Talking to the care recipient's solicitor and asking about the terms of the will can help to avoid unpleasant surprises later on.