

The background of the cover features a photograph of a room filled with numerous cardboard boxes, suggesting a moving or storage situation. On the left side, there is a large potted plant with long, green, feathery leaves. The scene is lit with warm, yellowish light, creating a soft atmosphere. The entire image is overlaid with a semi-transparent green filter.

Decision-making about the

best place

of **palliative care**

for people with

intellectual disabilities

A guide for care staff and

healthcare professionals

providing palliative care for people

with intellectual disabilities

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Table of Contents

<i>Preface</i>	4
<i>Note for the reader</i>	5
<i>Introduction</i>	6
<i>Summary</i>	7
<i>Considerations in decisions about a transfer to another residence</i>	9
Familiarity	9
The team's expertise	10
The home environment setup	11
Fellow residents or family members	12
<i>Different perspectives</i>	13
<i>Making the decision together</i>	15
Appendix: decision-making chart	19

► *The subject addressed by this guide*

This guide discusses how to decide whether people with intellectual disabilities (ID) should be transferred to a different setting in the final stage of their lives. Such decisions are often difficult and can lead to dilemmas for people with ID, their relatives and care staff. For example, ‘Should we opt for a different place of residence that is better equipped for palliative care, but may not be somewhere that the person with ID feels secure?’ When confronted with such dilemmas, care staff and healthcare professionals need support. This guide is a tool that can help take decisions in such situations.

► *The study on which the guide is based*

This guide is originally based on a Dutch study of potentially difficult transitions in the palliative care of people with intellectual disabilities. The study was performed by the Netherlands Institute for Health Services Research (NIVEL) in combination with the EMGO Institute for Health and Care Research/vu University medical center and the Koraal Groep. It was funded by the Netherlands Organisation for Health Research and Development (ZonMw). The study included an examination of the literature and group interviews with people with ID, relatives, care staff and physicians. A survey was also carried out among care staff* and doctors**. The study was carried out in The Netherlands.

► *Translation and modification of the guide to the European context*

This guide was originally written in Dutch. With help from *Irene Tuffrey-Wijne* and five other experts from five different European countries this guide was modified to a broader, European context. As health care systems and policies differ across Europe, some parts of the original guide were generalised, to make it more applicable in other countries. Although the provision of palliative care and the housing options of people with ID vary across countries, we hope this guide is a tool and inspiration for those who wish to provide the best possible place of palliative care for people with ID.

* The care staff who participated in the study were social workers and nurses who are specialised to support people with ID in daily life. The amount of support they usually provide depends on the needs of their client population, and may vary from a couple of hours per week to 24 hour support.

** Two types of doctors participated in the survey study: general practitioners and ID physicians. In the Netherlands, people with ID are generally cared for by general practitioners or ID physicians. Dutch ID physicians are physicians who have received three-year specialist training in the care for people with ID and who are generally employed by an ID care service.

► *The groups addressed by this guide*

This guide is compiled for care staff, doctors and other healthcare professionals who provide palliative care for people with ID*. The guide also describes the preconditions for taking decisions about the place of palliative care for people with ID, which makes it a useful tool for managers and policy makers as well.

► *How to use this guide*

There is no fixed set of considerations for deciding whether or not a person with ID should be transferred to another residence; it all depends on the situation and the needs of the individual person. This guide is a tool that can help care staff and healthcare professionals take decisions in conjunction with the person with ID and their relatives. The guide gives an understanding of the key considerations and values when taking decisions about the final place of residence. It also describes the steps to take when making a joint decision.

► *Decision-making chart*

The appendix contains a decision-making chart that can be used as an aid when dealing with issues concerning the place of residence.

► *Guide setup*

The guide starts with a brief introduction to palliative care and talking to people with ID about being ill and dying. This is followed by a summary of the key points from the guide. Next, there is a discussion of the relevant considerations when deciding on the place of residence, the different perspectives of the people involved and the steps for taking joint decisions.

* The background, training and qualifications of those who support people with ID vary across European countries. Amongst them are support staff with limited educational qualifications, social workers and nurses specialised in ID. In this guide we use the term 'care staff' for those who support people with ID in their daily life. European countries also differ in the type of doctors that offer medical care to people with ID. Among them are general practitioners, psychiatrists and physicians specialised in ID care. In this guide we use the general term 'doctor', for the physicians involved, irrespective of their educational background.

► *Palliative care*

Palliative care is the care aimed at the quality of life of people with a life-threatening illness that is expected to result in the patient's death. Palliative care covers many different areas. It refers not just to medical and nursing care but also to psychosocial and spiritual support, provided for instance by talking to the person with ID about being ill and by being present when they need it. Medical care has improved to such an extent in recent decades that people with ID are living longer. But this also means they often suffer longer from conditions that eventually lead to their death. The combination of complex medical problems, behavioural problems (in some cases) and limitations to verbal communication can make the provision of palliative care for people with ID particularly difficult.

► *Choices regarding where to live*

People have to make difficult choices in palliative care, for example regarding the best place for someone to receive palliative care. Many people in general, and many people with ID as well, prefer to remain in their usual home environment. Yet, that is not always possible. Can the person with ID stay in their own home* or would it be better if he or she is transferred to a different place, such as a setting offering more intensive care, a nursing home, a hospice or the home of a relative?

► *Talking to people with ID about being ill and dying*

Talking to someone about their situation, their illness and their prognosis is an important part of decision-making in palliative care. People with ID vary a great deal in their comprehension and understanding of their illness, which is why many care staff and healthcare professionals find talking about the illness and death tricky, as do relatives and other close acquaintances. Indeed, communication on this subject is not easy. Delivering bad news is a process rather than a single event. To communicate successfully, it is important to break up the information and provide it in small pieces, and to use the person in question's own frame of reference (Tuffrey-Wijne, 2012).

* By 'own home' we refer to the place where the person with ID is currently living. Living arrangements of people with ID vary, depending e.g. on the capabilities of the person and on the accommodation options available in their country. 'Own home' can therefore refer to e.g. a house or apartment owned or rented by the person, a family's home, a community (group) home, as well as a residential home.

► *Four considerations when deciding whether a person with ID should be transferred to another residence*

- *Familiarity:* It is particularly important for people with ID to be around people who understand them and are able to quickly pick up signs that they are in pain, for instance.
- *The team's expertise:* The first step for a professional team is to determine the care requirements, the expertise they already have, the additional know-how they will need to bring in and whether 24-hour care can be provided.
- *The home environment setup:* Is the home properly equipped for providing palliative care? For example, is there room to put a raised (or lowered) bed and to receive visitors, are there patient hoists available and is it possible to install medical equipment?
- *Fellow residents or family members (for people living together):* Palliative care for a person with ID living with other people can be valuable to both the patient and the other residents. Yet, care staff and health care professionals need to continually ask themselves whether they are able to provide the additional care for the sick person and care properly for the other residents.

► *Different perspectives on what is the best place for palliative care*

• *The person with ID: their own perspective*

People with ID often find it important to be surrounded by familiar people and things. But they also find the care they can get in their own home important, for instance the right medication, personal care and the ability to call for assistance at any time.

People with ID vary in their understanding and comprehension of their illness, and relatives and professionals often find it difficult to understand what people with limited understanding and comprehension are trying to communicate. Specific skills are needed, such as the ability to listen attentively, to find out what that person finds important. Knowing the life story of the person with ID can also help in identifying what they find important in their home environment.

• *The relatives' perspective*

Relatives also often attach importance to the person with ID being in their usual and familiar environment, and the criticalness of relationship based care is well documented. However, sometimes they feel the person with ID would be better off being cared for somewhere else, e.g. in a nursing home or hospice. In the final residence, relatives and care staff will often start a joint care process. Jointly delivering care can be of great value to the person with ID, but it can also be difficult if relatives and care staff have different ideas about what care should be provided. In such circumstances, a care plan drawn up together can remove worries and be used for guidance.

• *Care staff and healthcare professionals' perspective*

Care staff frequently have a strong desire to continue the support the person they have cared for because of the close relationship they have developed. The wishes of the person in question and the relatives are important to them. Doctors also often feel someone with ID is best off staying at home. They attach importance to the wishes of the person with ID, but they find the expertise and resources available to support optimal palliative care also important factors. Teams that do not know what they would be facing need support in determining whether they have the right expertise and equipment. Teams also need support themselves, by counselling or supervision, as providing care to a dying person with ID can be emotionally demanding.

► Taking a joint decision on the place of residence

- *Prior to taking the decision*
It is important to consider at an early stage (if possible, even before people become ill) what supports would be required to enable the person with ID to die in their own home.
- *Steps in deciding whether the person with ID should be transferred to a different setting*
(NB These steps are one example, but they do not have to be followed rigidly in practice.)
 - 1 Appoint a coordinator, for instance a team leader, case manager, palliative care expert or care staff member, to coordinate the decision making concerning the possible transfer.
 - 2 Determine which relatives, legal representatives, care staff and healthcare professionals should be involved. Inform the person with ID, and the other relevant people of the steps to be taken in the decision-making process.
 - 3 Schedule a meeting with all the people involved.
 4. Make clear before the meeting what responsibilities the different people involved have in the decision-making process.
 - 5 In the meeting, the coordinator should make sure that all the people involved mention the considerations they want taken into account and should ensure they are as open as possible to the ideas of others. The person in question's wishes should be made explicit by the people who know them well if that person cannot do this themselves.
 - 6 Discuss all the considerations. Give due attention to the familiarity of the home environment, skills of care staff and healthcare professionals, continuity in the care, the atmosphere in the team, and the emotional security and physical safety of the person with ID and their fellow residents. Attention should also be paid to the more implicit considerations, such as the personal convictions of relatives and staff. Discuss alternative places of residence too.
 - 7 Simplify the information so that the person with ID can take part in the decision-making process to the fullest extent possible.
 - 8 The people involved take a joint decision concerning the place of residence.
 - 9 Document the agreements in a care plan.
 - 10 Carry out regular evaluations with all those involved to check that the decision taken is still the best option.

Familiarity

Carol about Anne

Anne and Carol both have ID. Anne is seriously ill. Carol is helping to decide where would be the best place for Anne to spend the remainder of her life: 'I think that Anne wants to die at home, because she wants to be in her own home. She has lived there such a long time and that's why she wants to die there too... She lived her life in her own home. Then she can go to the market too, eat fish and chips, she loves that. Then I can help her, go shopping, take her on walks and things.'

People should be able to choose their own place of residence. This is reflected in the Convention on the Rights of Persons with Disabilities of the United Nations, which states that 'Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement' (Art. 19 UN CRPD). When people become ill, they generally prefer to remain in their own home close to the people they know well. This guiding principle applies to people with ID as well. Home is a familiar place with familiar things and familiar people. Furthermore, the person with ID can continue their activities for as long as they can manage, such as making a cup of tea or going on walks in the familiar neighbourhood. Their familiar home environment gives a sense of structure and security. Many people with ID have already lived in a particular place for a long while by the time they become seriously ill. They have developed close contacts with e.g. care staff or fellow residents. Many people with ID find communication difficult and are not good at informing others of complaints such as pain. It is particularly important for them to be around people who understand how they communicate and can quickly pick up signs that they are in pain, for instance. A care staff member: *'There were trusted and familiar faces all around her, both care staff and fellow residents, who knew her wishes and preferences.'*

The person with ID may have strong ties with fellow residents. A care staff member: 'It was good for him and his fellow residents to remain in his home environment. The other residents could pop in on him and they were able to say goodbye properly.'

Relatives and other close acquaintances also find familiarity important. Parents in particular can find it difficult that their child has a home away from the family. A mother: *'Our wish had always been to care for him at home (the parents' home) in his final days. But the journey home would have been too tiring for him. So then we said he should stay in the residential home because that was basically his second home in a way. The care staff have known him and us for ten years now.'*

CORE MESSAGE

When people with ID are in the final stage of their life, it is particularly important for them to be close to people who understand how they communicate and who can quickly pick up signs that they are in pain, for instance.

Expertise within the team

Can we give John the right care?

John has lived in the same group home for 25 years now. When he is 70, he gets incurable cancer of the oesophagus. Seriously ill people with ID are sometimes moved to a place offering more intensive nursing care. This is an unsettling period. John does not want to move, and the team would like John to stay in his current home too. But are they able to provide the right care? The team is divided on the matter; they have never given palliative care before. Many of the care staff are trained in social welfare and do not have any nursing expertise. They would also need to be available to provide care 24 hours a day in the home. The care staff are uncertain what will happen when John becomes sicker.

Seriously ill people with ID often require intensive support and care. That places high demands on the quality and availability of the care. In addition to psychosocial support, nursing expertise is extremely important, for example for pain relief and inserting probes and catheters. Seriously ill people with ID must have access to care 24 hours a day. However not all teams will be able to offer the right expertise and continuity in care.

► *Expertise available?*

In order to be able to take a decision on whether John can stay at home, his team has to know what expertise John needs, what expertise is available in the team and what expertise is lacking. It is also important to know how team members feel about providing palliative care. Care staff who have no experience with palliative care usually do not know exactly what expertise is required. They are on the point of losing someone whom they may have cared for over a long period. In this new, stressful situation, care staff can lose their 'sense of direction' on what care to offer. This can make them insecure and can put pressure on the care relationship they have with the person with ID.

When assessing the care requirements and expertise needed, it is important for the care staff to consult a doctor, team leader or expert in palliative care as well. It is often easier to find a solution if team members feel safe discussing their own know-how and doubts. Not all teams know that they are able to call on assistance, for instance. In addition to expertise, there is often quite simply a need for more staffing resources, to enable 24-hour access to care.

Options for accessing expertise on palliative care in ID care vary across Europe. Options include:

- training of care staff working in ID care, e.g. in inserting feeding tubes or operate a morphine pump
- strengthening partnerships between ID care services and palliative care teams, for example to enable palliative care experts (e.g. specialist nurses) to provide nursing care to people with ID at home
- joining (regional) palliative care networks

CORE MESSAGE

Not all teams have the right expertise and experience and can offer sufficient continuity to provide proper palliative care. The first step for a team is to determine the care requirements, the expertise they already have, and the additional know-how and staffing resources they will need to obtain.

Home environment setup

Doctor on Jake's home:

Jake simply couldn't stay in his home. He lived in a top-floor single-family flat. There were no rooms in his flat that could accommodate a wheelchair or nursing in bed. The doors were too narrow and Jake's bedroom was too small to install all the equipment.

The care for a seriously ill person with ID places demands on the setup of the home environment. Many people end up confined to their bed and are no longer able to walk without support. In such circumstances, it can be very inconvenient to have the bed on the top floor of a house or flat. Sometimes it is not possible to put a (raised or lowered) bed on the ground floor. Some people require medical equipment or devices such as a morphine pump, artificial respiration equipment, a patient hoist or an alarm system. Not all homes are suitable for the installation of such equipment and devices. In addition, group accommodation can sometimes be so small that there is no secluded place for receiving relatives, leading to a lack of privacy. In such situations, the person with ID may need to move to accommodation adapted to their needs.

In a couple of European countries it is increasingly common for age-proof accommodation to be built. The idea behind age-proof accommodation is that it should be appropriate for all phases in life, including for the elderly and for people with disabilities. Residents can continue to live there as their health care needs change, in theory until the end of their life ('ageing in place'). Even so, many homes are still not suitable for palliative care.

CORE MESSAGE

Not all homes are 'age-proof' and suitable for palliative care. It is necessary to determine whether the home is set up for this, for example whether it is possible to put up a bed downstairs, install a patient hoist and install medical equipment.

Fellow residents or family members

Rachel in the living room

Rachel lives in group accommodation for people with ID and behavioural problems. When she becomes seriously ill, the care staff wonders what effect her illness will have on her fellow residents. It is a tough, worrying period for Rachel; she needs peace but also needs to be near her care staff. The team considers putting Rachel's bed in the living room so that she can always be close by. But how will the fellow residents react to this? They are all people with ID who need a lot of structure and a safe environment. And will Rachel get enough rest that way?

The presence of fellow residents can be unsettling for a seriously ill person with ID living in group accommodation. Vice versa, a seriously ill patient can also affect their fellow residents. Many people with ID require structure and a safe environment, and the care for a sick patient can cause a great deal of unrest and an unclear situation for the others. The sick person requires considerable time and attention, so that there is less time left for the fellow residents. The other residents are confronted with the illness, and ultimately the death, of someone with whom they have shared their lives. This can have a huge impact. Not all people with ID understand what it means for someone to be sick or how to deal with that.

Care staff are faced with a tough task: not only do they have to provide additional care for a seriously ill patient, but at the same time they are also responsible for the care of a group of fellow residents, who probably need a lot of attention during this period. Some may be reluctant to live together with a dying person. Wishes of fellow residents have to be acknowledged as well. That can give rise to the question whether it might be better to transfer the sick person to another residence.

People with ID can have strong bonds with one another. If a sick resident moves, they lose a source of support and security in one go. An early departure can also feel unsafe for fellow residents: *'Suddenly she was gone. We couldn't say goodbye. After all, she was one of us. I'd rather she'd stayed with us. But we weren't allowed to choose.'* Communicating openly with other residents about the sickness and death of a fellow person with ID helps them in the process of dealing with this.

If the person stays with family, the care for a dying person may also have huge impact on the members of the family. Good palliative care therefore also means good care for them.

CORE MESSAGE

Looking after a person with ID in the vicinity of their fellow residents can be important to both the patient and the other residents. Healthcare professionals need to ask themselves continually whether they are still able to both provide the additional care for the sick person and still care properly for the other residents. Wishes and needs of fellow residents and family members have to be acknowledged as well.

The previous chapters covered the considerations that come into play when deciding whether a person with ID should move to another residence for palliative care. Decisions about the place of residence often involve various different people: the person with ID, their relatives and care staff, all of whom have their own ideas about the place of residence. We will now look at these different perspectives.

► *Perspectives of people with ID*

People with ID who understand their illness and can communicate their wishes clearly regarding where they want to live often find it important to be able to stay in their usual home environment surrounded by familiar things and people. But they also find the care they can get important, for instance the right medication, personal care and the ability to call for assistance at any time.

However there are also people with ID who realise they are ill but do not understand what that means. For example, they cannot (fully) comprehend what might happen as the illness progresses or what it would mean to move to a different place of residence. Then there are also people with IDD who have little or no awareness of their illness. A trusted environment and proper care are important for them too, but it is more difficult to find out what their wishes are. The combination of poor cognitive ability and a serious somatic illness can make communication very difficult for relatives and care staff. Specific skills are needed, such as the ability to listen attentively, to find out what that person thinks is important. Relatives and care staff who know the person with ID well are often best able to make contact with them and interpret the signs they give. Knowing the life story of a person with ID can also be informative about what they find important in their home environment.

The life story

Information about the life story can serve as input for the requirements regarding the final place of residence. A life story shows what people find important and reveals how people give shape to their lives and their relationships. A life story can for example show what places the person with ID likes to visit, where they go to find peace and quiet, who they like to have around them, how they respond to changes and what activities they like. Someone's life story is continually changing, like life itself. Healthcare professionals need to be good at listening, observing and reflecting in order to get a picture of the person's life story.

► *Perspectives of relatives*

Many people with ID have relatives or other close acquaintances who are involved in key decisions. Some relatives act as legal representatives. Relatives generally acknowledge the importance of a familiar environment and can even be pleasantly surprised by the possibility of the person with ID remaining in their own home. A brother: 'When we heard that my sister had become ill, we wondered where she would have to go. We didn't think for one moment that she would be able to stay with her residential group. It was a huge relief to us when this turned out to be possible after all.' If the person with ID is able to stay in their current home, this means the relatives, care staff and healthcare professionals may embark on a joint care process. As a result, relatives or other close acquaintances may end up spending a great deal of time, even at night, in the person's home. Caring together for the sick person with ID can be very valuable as the patient is then surrounded by all their familiar people. However, jointly delivering care can also be difficult if relatives and care staff have different ideas about what care should be provided. This is an intensive period for all those involved in which emotions can run high. In such circumstances, a care plan drawn up together can remove worries and be used for guidance.

However, relatives or other close acquaintances sometimes feel the person with ID would be better off being cared for somewhere else, such as in a nursing home or in a hospice. That could be because the relatives have had positive experiences with a particular hospice or nursing home and they want their relative to enjoy that high-quality care as well. A sister: 'I wanted to give her [my sister] the best, I've provided that care for years. And I have had to fight so hard for so many things. Basically, there's often a lot wrong in the care for people with ID. I've tried to arrange a lot of things for her on the ground. It's a struggle every time. So when she gets ill you start to panic and you think: OK, but I don't want her to end her days here.'

► *Perspectives of care staff and healthcare professionals*

If a person with ID becomes seriously ill, care staff can respond in very different ways. Care staff may feel afraid, for instance because they feel they are not properly equipped and are too inexperienced to provide palliative care. Teams that do not know what they will be facing need support in getting a clear picture of what they can expect as the illness progresses and in determining whether they have the right expertise and equipment. Even so, many care staff members have a strong desire to 'complete' the care for the person with ID themselves because of the close relationship they have developed. They feel that the person with ID can best be cared for by their trusted caregivers who know them well. ID care staff may also think that healthcare professionals not specialised in ID care would not be as good at caring for a sick person with ID. The care staff attach great importance to the wishes of the person with ID, and to the relatives' wishes. The care staff have a very valuable role in revealing the person in question's wishes because of the close care relationship; they often know the person extremely well. However care staff sometimes have little time to pause and reflect as they are so intensively involved in the care for the incurably ill person with ID. That can make it tricky for the care staff to distinguish between that person's wishes and their own wishes. This is why the care staff themselves need support too. This 'care for the carers' should provide care staff with emotional support and a safe environment in which they can discuss decisions about the place of residence openly. Doctors also often feel someone with ID is best off staying in their usual home environment, if at all possible. They attach importance to the wishes of the person with ID, but they also think it is important to have high-quality care.

In this section we describe how to take account of the different perspectives and jointly arrive at an answer to the question *‘What is the best place of residence for this person with ID who needs palliative care?’*

► **Explicit and implicit considerations**

There are no fixed criteria when answering the question of what would be the best place of residence for the person with ID as the criteria depend on the person’s situation. The requirements for the place of residence for a specific person with ID need to be determined by the people involved. To make a sound decision, the people involved need to have a good understanding of the relevant considerations for this decision about the place of residence, such as how familiar is the environment, is there sufficient expertise within the team, what is the home environment setup and what is the position of other residents? However, there are often other, more implicit considerations, such as uncertainty among the care staff about what they will be faced with, or distrust of the care institution among relatives. When coming to a decision, it is important to unearth the more implicit considerations as well.

► **Weighing up different values**

The considerations mentioned above regarding the place of residence are based on various values. For example, the values connectedness and the person with ID’s emotional security play a role in the consideration of how familiar the environment feels. The consideration of the expertise within the team involves the values of the team’s expertise, continuity of care and the stability of the team. The value of the person with ID’s physical safety plays a role when considering the setup of the home environment. And the emotional and physical safety of both the person with ID and their fellow residents is involved in the consideration of the position of the fellow residents. Respect for the autonomy of the person with ID can also play a role if the person with ID wants to live somewhere that is not in line with the opinion of their caregivers or relatives. What people think makes a good place of residence is subjective. Other values than the values listed above may also be involved.

If it is difficult to decide on a place of residence, that is often because of different, conflicting values, for example between the person in question’s bond with their caregivers and the team’s expertise. The people involved in the decision need to adopt an investigative, reflective attitude in order to weigh up the values and decide which is most important in this specific situation.

Experience and intuition are important here along with insight into what is possible with the person with ID’s home and that person’s own preferences.

Information is also needed concerning the extent of the care needs, how the illness can be expected to progress, the costs and the necessary expertise and resources.



► *Who should be involved?*

A decision about the place of residence cannot be taken by just one person. The people who should be involved need to be identified; often this will be the actual person with ID, relatives, a legal representative (if appointed), the care staff, the doctor, a behavioural expert and other healthcare professionals, depending on the healthcare needs of the person. All these people will have ideas about the best place of residence based on their relationship with the person with ID. They need to discuss the possible places of residence together with the person with ID and with each other.

► *Responsibilities in the decision-making process*

Care staff have a responsibility to identify the wishes of the person with ID and the relatives' wishes regarding the place of residence, and they should ask actively and openly for this information. Doctors have a responsibility to assess whether it is possible to deliver care that is medically sound in a particular home. Care staff are responsible for discussing with the team whether they have the expertise and staff they need to provide palliative care. Legal representatives, if appointed, will also have specific responsibilities in decisions, which will depend on the representatives' role and authority. Legal models for substituted decision making differ across Europe.

It helps if one person coordinates the decision-making process as so many people are involved. The coordinator can be, for example, a team leader, case manager, palliative care expert or care staff member. It is good to remember that the person with ID's relatives may have a different perspective on what constitutes the best place of residence. The decision-making process can only have a satisfactory outcome if all those involved are prepared to make the effort and to be open to input from others.

Care staff and healthcare professionals have a responsibility to identify the wishes of the person with ID and the relatives' wishes. Doctors are responsible for determining whether medically sound care can be delivered in the home. Care staff are responsible for investigating whether they have the necessary expertise and staffing resources. Legal representatives, if appointed, will also have specific responsibilities in decisions. Make sure that there is one practitioner coordinating the decision-making process.

► *Decision-making as a process*

Decision-making is a process. Decisions are not usually taken in a single instant; they are often preceded by various discussions. It can be worthwhile to examine the options for looking after the person with ID at home at an early stage, before the person with ID becomes seriously ill, as this can speed up the decision-making process later on when things may be more hectic and it may be more difficult to find the time. A sound, respectful relationship between the person with ID, their relatives and the staff is an important foundation for all decision-making processes as people will then be more likely to be open-minded about the ideas of others and to take joint decisions that enjoy the support of all.

The place of residence can be the subject of informal discussions with the person with ID and their relatives but it is also a good idea to schedule a formal multidisciplinary meeting with relatives or other close acquaintances once a potential move is actually on the cards. Agreements can be documented in a care plan. Any decision or route taken needs to be evaluated on a regular basis; after all, it is never possible to predict

exactly how an illness or the needs of a person with ID will develop. If the person with ID develops new and complex health problem, for example, or indeed if their health improves, there needs to be a reassessment of what is the best place of residence. Regular evaluations should also be made to check that the responsible team has the right expertise and staffing resources. This means it is important to remain in a dialogue with all the people involved.

Decisions are not taken in a single instant. The decision-making process can be facilitated by considering the options for the person with ID, before they become seriously ill. A sound relationship between the person with ID, care staff and relatives is an important foundation for all decision-making processes. Document agreements in a care plan so that they can be evaluated later on.

► *Alternative residences*

Sometimes a transfer to another residence as the final residence is the better option. Options may include an ID home with more intensive care, go to stay with relatives at home, a nursing home or hospice. Care staff specialised in working with people with ID do not always have a picture of what alternative places of residence are on offer, especially the options outside their own work environment such as hospices and nursing homes. ID care staff sometimes doubt whether other professionals would be able to communicate properly with their person with ID and respond to their care needs. On the other hand, hospices and nursing homes have a great deal of expertise in-house in palliative care. A picture of the accommodation options is needed to weigh up the alternatives properly.

Palliative care provision for people with ID varies across European countries. Outside ID care, people with ID mostly depend on mainstream palliative care services. Initiatives specifically designed for people with ID are scarce.

Among the few initiatives are:

- volunteers trained in both palliative care and ID care, who are able to support the ill person with ID at the place where they live
- nurses working in mainstream palliative care services with expertise in ID
- hospices or units specifically set up to offer palliative care to people with ID

These initiatives seem to flourish when (local) palliative care services and ID care services are committed to collaboration.

► *Jointly with the person with ID*

Sometimes it seems as if the wishes of the person with ID are not (or are no longer) being given priority because so many considerations and arguments come into play in the decision about the best place of residence. The possibilities of modifying the home setup and the expertise of the care staff often play a role alongside the wishes of the person with ID, especially if that person has very complex care needs. There are often different advantages and disadvantages to each of the options: if the person with ID is moved, they will miss their familiar environment, but if they stay they may not get certain kinds of care or treatments. Care staff and healthcare professionals and relatives may find it difficult to present such a choice to a person with ID.

There are cases where a person with ID only hears that they will be moving after the decision has been taken. This is because relatives and staff want to protect the person with ID and do not want to worry them unnecessarily. Sometimes no clear idea is obtained of what the person with ID wants. It is important to realise that the interests of the person with ID can sometimes be closely interlinked with those of relatives or healthcare professionals. Getting an explicit statement of the person with ID's wishes requires a proactive approach. A different weight will need to be given to the wishes of someone who has a good idea of the consequences of their illness compared with the wishes of someone who does not properly understand what effect their illness or a move will have. A good assessment of what the person with ID is able to comprehend is therefore indispensable when coming to the decision. It is also important to simplify the information about the decision to such an extent that the person in question is able to participate in the decision-making process.

Jointly coming to a decision with the person with ID means that their wishes must be made explicit and must not be confused with the interests of staff and relatives. This also means that all information should be simplified to such an extent that the person with ID has a genuine chance to participate in the decision-making process. To do this, a good assessment is needed of what that person is able to comprehend and what they understand of their illness.

► *If the person with ID moves to another residence*

If it is decided that it is in the person with ID's interests to move, they will require a great deal of support. Leaving their trusted environment is a difficult situation for that person, which is why it is important for them to be involved at all stages in the move. The person with ID's feelings must be acknowledged and they must be given the scope to express their emotions. The new staff need help from the relatives and the 'old' care staff in interpreting the person in question's behaviour and recognising signs so that the new place of residence can be made as accommodating as possible. They can work together to draw up a new care plan. The person with ID will settle in and feel safe more quickly if their relatives and friends, 'old' care staff and 'old' fellow residents remain involved and pay regular visits.

► *What is the best place of palliative care for a person with intellectual disabilities (ID)*

Identifying the considerations

The familiarity of the home environment

- Is it known where the person with ID would prefer to live? Which care staff, relatives, or other close acquaintances are best able to communicate with that person and find out what they want?
- Where does the person with ID feel at home? What things, activities and people are important to them?

The team's expertise

- What care is the person with ID expected to need?
- What know-how, expertise and experience in palliative care is there in the team and what expertise is lacking?
- What staffing resources are available and is it possible to deliver care 24 hours a day?
- What staffing resources and expertise can be brought in, for instance by training care staff or by deploying palliative care experts.
- How do the team members feel about providing palliative care? Talk openly about doubts and uncertainties.

The home environment setup

- Is the person with ID's home properly equipped for providing palliative care? For example, is it possible to install a raised or lowered bed, receive visitors, and install patient hoists and medical equipment if necessary?

Fellow residents or family members

- What is the relationship like between the sick person with ID and their fellow residents or family members? How could the fellow residents or family members be involved in the care and support for the sick person?
- How stressful would it be for the sick person with ID if they stayed living with their fellow residents or family members?
- How stressful would it be for the fellow residents or family members if the sick person stayed living with them?
- Can the team combine the additional care for the sick person with the care for other residents, who will also need more attention during this period? How long does the team expect to be providing this extra care?

► *Steps for making a joint decision*

*Steps in deciding whether the person with ID should be transferred to a different setting
(NB These steps are one example, but they do not have to be followed rigidly in practice)*

- 1 Appoint a coordinator, for instance a team leader, case manager, palliative care expert or care staff member, to coordinate the decision making concerning the possible move.
- 2 Determine which relatives, legal representatives, care staff and other professionals should be involved. Inform the person with ID, and the other relevant people of the steps to be taken in the decision-making process.
- 3 Schedule a meeting with all the people involved.
- 4 Make clear before the meeting what responsibilities the different people involved have in the decision-making process.
- 5 In the meeting, the coordinator should make sure that all the people involved mention the considerations they want taken into account and should ensure they are as open as possible to the ideas of others. The person in question's wishes should be made explicit by the people who know them well if that person cannot do this themselves.
- 6 Discuss all the considerations. Give due attention to the familiarity of the home environment, skills of care staff and other healthcare professionals, continuity in the care, the atmosphere in the team, and the emotional security and physical safety of the person with ID and their fellow residents. Attention should also be paid to the more implicit considerations, such as the personal convictions of relatives and staff. Discuss alternative places of residence too.
- 7 Simplify the information so that the person with ID can take part in the decision-making process to the fullest extent possible.
- 8 The people involved take a joint decision concerning the place of residence.
- 9 Document the agreements in a care plan.
- 10 Carry out regular evaluations with all those involved to check that the decision taken is still the best option.