

Huntington Disease

Caregiver Management

**Neurogenetic
Clinic**

Groote Schuur Hospitaal

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The disease that your relative has is called **Huntington disease**.

PURPOSE OF THIS HANDBOOK

The aim of this handbook is to familiarise you with Huntington disease, so that you can recognise its symptoms and know what to expect as it progresses. By reading the two booklets every now and then, you will be able to see that many of the difficulties your relative is facing are part of the symptoms of the disease. Included are some general principles of care and tips that other caregivers have found helpful. Although you may find it depressing to read about the course of the disease when he still has only mild symptoms, remember that by anticipating some of the changes that he and you will face as the disease progresses, you'll be better prepared to find ways to deal with these challenges when they do arise.

It is important that you read the "General Information" booklet first so that you can have a good understanding of the symptoms of the disease, inheritance pattern and the difficulties which your relative is dealing with and having to come to terms with.

DIFFICULT BEHAVIOURS SOME CAREGIVERS MAY EXPERIENCE WHEN CARING FOR A RELATIVE WITH HUNTINGTON DISEASE

It is important to recognise that patients with Huntington disease develop certain behaviours because they are due to the changes in the brain itself and that is why they may become frustrated, depressed or irritable which they never were before they developed the symptoms. However, at the same time, they are also reacting to the way the disease is affecting their lives by their loss of independence or the fear of what will happen in the future. In some people who always have had personality traits of irritability or mood swings, these might become exaggerated with the disease.

Mood changes: Sometimes the person becomes withdrawn and irritable. At other times he easily gets over-excited and agitated and is overactive and restless. He easily becomes angry and aggressive which is frightening for the caregiver as the outbursts are unpredictable.

Lack of awareness: The person is unaware of his movements. He used to do routine tasks quickly and carefully and always finish them. Now he needs to be reminded to do them and then does not take any care about how he does them and often doesn't finish doing them.

Lack of insight or denial: He refuses to see a doctor as he doesn't think that there is anything wrong with him. He gets irritable and angry when others try to help him with tasks that he no longer can do properly. He used to be very loving and gentle and supportive of his wife and family, but now he is unconcerned about them and does not seem to notice if someone is upset or distressed.

Rigidity of behaviour: The person is very demanding. He does not like any changes in the home or his routine. When he wants something done he wants it done immediately and won't wait even though the caregiver is busy with some other task like attending to a child. He is also stubborn, refusing to change his clothes when they need to be washed or turning the TV volume down when others want to talk.

Loss of inhibitions: His behaviour in public is often embarrassing. He may drink from someone else's glass, use offensive language or speak disparagingly about a person within hearing distance of the person. He may become extremely sexually demanding. This may also be at inappropriate times or in appropriate places.

Initiative and drive: The person no longer contributes to doing household tasks and does not notice that his partner is having

to take on his responsibilities as well as continue with her own duties. He does not notice whether the house is in a mess and that it would help if he did some of the tidying up or washing. He seems to be happy to just sit in front of the TV all day long and do nothing.

Organisation and planning: He can't seem to organise himself to do simple tasks such as getting dressed or taking a shower or cleaning his teeth. He constantly needs to be reminded of what he is doing and what he needs to do next. He may put his socks and shoes on first and then cannot get his trousers on over them or puts his clothes on back to front or inside out.

MANAGEMENT OF SOME OF THE PRACTICAL DIFFICULTIES ASSOCIATED WITH HUNTINGTON DISEASE

Driving

Once the patient has been diagnosed with Huntington disease he should consult the doctor at each clinic visit with regards to driving and when it would be wise to stop driving vehicles, especially when you (the caregiver) notice that he is not driving as well as he used to do. Frequently patients will not realise that their judgements and reactions have become slower and they have accidents before becoming aware that their impairments have become a danger to driving. This may lead to injury of, not only themselves, but to the general public too.

Medication

It is important that the person takes the medicine prescribed by the doctor for a few weeks as some medication takes two or three weeks to become effective. Patients may experience side effects such as a dry mouth with certain medicines, but they should not be discontinued without first consulting the doctor as

some of them take several weeks before they benefit the patient.

Routine appointments should be kept so that the doctor can monitor the action of the medication and regulate it accordingly. This might mean prescribing a new medicine, increasing or decreasing the dose of the current medicine, or taking the person off the medication.

As the person's symptoms develop the medication prescribed early on may no longer be effective or may even be harmful.

Community's attitude to patients gait and speech

Sometimes community members may comment on the patient's gait and speech and consider him to be drunk. Medic Alert bracelets can be ordered for the patient to wear which will indicate that he has Huntington disease. The clinic can also provide you with a letter explaining the symptoms of the disease which you can show to community members who claim he is drunk.

Social benefits

Once the patient is no longer able to work he is entitled to and should apply for a disability grant from the South African Social Security Agency (SASSA).

Later on, should the spouse or adult child have to stop working to care for the patient, she is entitled to apply for a grant-in-aid through the SASSA.

If the parent is on a disability grant the family is entitled to apply for a school fees rebate for the children.

Movements

Although the movements that the patients often display look exhausting and are irritating to others, patients are frequently not aware of them nor do they find them a nuisance, so it is not

always necessary for the doctor to prescribe medication for them.

Movements are often increased when the person is hungry or anxious. Therefore, it is important to keep the patient well fed and to provide a calm, predictable environment.

If the movements are sufficiently severe to cause him to slide out of his chair or to fall out of bed it is easier to change his seating and sleeping arrangements than to try to reduce his movements. These can be done by:

- Attaching padding where necessary around his elbows, shins and ankles to avoid injury when bumping against furniture surrounding the chair or bed;
- Restraining belts loosely tied around his hips and chest when sitting in a kitchen chair at the table;
- Sitting in a padded sitting room chair with a sandbag as a weight to provide additional support across his hips or feet to control the leg movements (Figures 1 and 2). You will need to experiment to see which way is the most effective for the particular person;
- The sandbags can be made by filling plastic shopping bags with sand and knotting the handles (Figures 3);
- Put the filled bag into another plastic bag with the knotted end to the bottom and knot the second bag so that the sand does not leak out (Figure 4);



Figure 1



Figure 2



Figure 3

- Placing protective pillows around the bed to prevent him from bumping against furniture or rolling out of the bed;
- Placing a double mattress on the floor for sleeping to prevent unnecessary falls when he is resting.



Figure 4

To avoid falling, patients should be educated not to do other tasks such as talking or carrying objects while they are walking. They should focus all their attention on the task of walking only. Walking frames are not a practical form of assistance in small houses or where the environment is sandy.

Sleeping

Patients with Huntington disease often have sleeping difficulties. Sometimes they sleep during the day and are awake all night. Other times they are very restless during the night and their movements and activities are disruptive to others in the house or those sharing the bedroom. Sleeping difficulties should be reported to the doctor as there are very effective sleeping tablets which can be prescribed for night use.

Lack of sleep at night is also a safety problem as the person may wander around the house, disturb the sleep of other members of the family, forget to lock doors and forget to switch off electrical appliances.

Smoking

Because of the risk of burning himself and causing fire, the person should always smoke outside or in a room with a cement or tiled floor. He should sit on a kitchen chair to minimise the risks of burning himself or causing a fire. This

relates not only to individuals who have movement and coordination difficulties, but to most individuals who have Huntington disease as they frequently have memory impairment from early on in the disease. They should definitely not smoke in bed and should develop a routine early on in the disease of smoking outside or in specific rooms only.

Communication

Communication becomes affected fairly early in the disease. You should do everything possible to make it easier to understand what the patient is trying to say and to be sure that he understands what you are saying. The environment should be quiet with no TV, radio or other conversations taking place. The patient should be calmed down and be asked to speak very slowly. You should also speak slowly and allow him extra time to think about what you have said. Use short sentences and allow him plenty of time to think about what he is going to say and for him to respond. Try not to interrupt his thoughts by repeating a question while he is thinking about what he is going to say. He should not be hurried and he should know that you are going to spend time to listen to him.

Patients with Huntington disease have difficulty in remembering things, but if they are prompted with words they can usually respond. It also helps to ask questions to which the patient has to say 'yes' or 'no'. Patients can understand much more than what they are able to say even in the latest stages of the disease. When speaking in front of a patient remember that he can understand what you are saying even though he might not be able to speak at all.

It is common for patients with Huntington disease to repeat themselves over and over again and get stuck on the topic. If possible try and distract him to get him off the topic. Sometimes it helps to tell him that you have finished with that topic and that you are now discussing something else.

FEEDING AND SWALLOWING

Patients can have swallowing difficulties from early in the disease. They first find it difficult swallowing liquids and later on have problems with solid foods. This is because they have difficulty in:

- closing their mouths and chewing;
- moving the food to the back of their mouth;
- co-ordinating their breathing in and swallowing;
- eating slowly without gulping their food down quickly;
- swallowing each mouthful completely until there is no more food left;
- swallowing when their mouths are dry from the medication they are taking.

Eating and feeding in general

Liquids are the hardest thing to swallow. Drinking warm and cold liquids through a straw helps to prevent choking. A flexible plastic straw in a plastic bottle like sports people use, guides the liquid to the back of the mouth and makes it easier to swallow. It also prevents spillage. These bottles and straws can be obtained from a supermarket at a reasonable price (Figure 5).

Remember that it is important that the patient drinks plenty of fluid especially in the summer time.

Be careful that the food is not too hot as the patient can burn his tongue or mouth.

If he has dentures which do not fit well, they should be removed before eating so that he only has to concentrate on chewing and not also on preventing his dentures from falling out of his mouth.



Figure 5

Let him take a swallow or two of liquid before eating food if his mouth is dry from the medication.

Encouraging the patient to eat or to be fed with a teaspoon will ensure that the bite sizes are correct and that they are a consistent size. This will prevent him from 'stuffing' as much food into his mouth as he can which can cause choking when he swallows.

The food should be cut into small bites and have a lot of gravy or sauce over it to make it moist and easier to swallow. Add custards or ice-cream to mashed fruits.

Choose soft, easy-to-chew and easy-to-swallow foods with the consistency of porridge. Later on the food can be purified or mashed so that it is soft and smooth. Many patients find it very difficult to eat rice and choke easily if the grains are not well mixed with plenty of gravy.

Many patients say they are always hungry so when they ask for more food soon after a meal they should be given a snack or another meal when it is coffee or tea time. It is better to serve 6 or more small meals throughout the day and while the patient is awake at night. This prevents constant hunger and may help to minimise gulping. It also reduces irritability, anger and movements. Small meals taken more frequently will also prevent choking.

The patient should eat until he feels full.

He should never try and drink a mouthful of liquid while he has food in his mouth as this will cause him to choke. He should first have a 'dry swallow' to ensure his mouth is empty before taking a sip of liquid or a spoon of food. This means that before taking a sip of liquid or mouthfull of food he should swallow, even if he thinks that his mouth is empty to be absolutely sure that there is no food or liquid left at the back of his mouth.

Mealtimes

The patient should eat in a room where there are minimal distractions such as TV, radio, conversations or people walking in and out of the room. Try and give him his meal on his own before the rest of the family eat theirs so that he can concentrate on chewing and swallowing and won't be distracted. This will also prevent him from getting hungry while watching others eat and he has to wait to be fed.

He should wear a plastic apron to prevent food from spilling onto his clothes. This saves a great deal of effort of changing and washing of clothes. The apron can be cut from a black garbage bag which is easy to put on and take off and can easily be wiped down after each meal (Figure 6).

He should sit in an upright comfortable position with sandbags for support on his hips or feet (whichever he finds most helpful) to help reduce the movements. He should sit at a kitchen table with his elbows supported on the table (Figure 7) or else in a sitting room chair with cushions behind his neck to support the head (Figure 10). His head should be upright with his chin pulled downwards and backwards as this helps to direct the food towards the throat and prevents him from choking (Figure 7 and 10).



Figure 6



Figure 7



Figure 8

He should take small bites of food that are easy to chew and should be reminded to eat slowly and concentrate on the chewing. He should put his fork or spoon down after each bite and be reminded to have a second 'dry swallow' before the next bite to be sure that the mouth is empty so that he doesn't choke. He should not talk while he is eating to avoid breathing in when swallowing as this will cause him to choke. The patient should never be rushed when he is eating or being fed.



Figure 9

He should remain seated in an upright position for 45 minutes after meals to avoid regurgitation.



Figure 10

He should eat all the same kind of food on his plate before going onto another food so that he does not have to adjust to different textures of food. For instance, he should eat all the bitesize pieces of meat before he starts to eat the peas and then finish by eating the mashed potatoes.



Figure 11

It is recommended that the food is placed in a cooking pot so that he does not spill the food when trying to get it onto his spoon.

Tips for Feeding

If the patient is able to maintain a good head position with his chin tucked in while you are feeding him, sit opposite him at the table so that he does not have to be distracted by trying to turn

his head to the side. If he is unable to maintain this position, stand behind and to the side of him to support his head with your body (Figure 9).

If he is fed while sitting in a padded couch put a rolled towel or pillow behind his head to keep his head upright and his chin downwards (Figure 10).



Figure 12

If he has to remain in bed ensure that he is propped with pillows and rolled blankets so that his head is in the correct position with his chin downwards to prevent choking (Figure 12).

Bathing

Even though it is difficult, it is important for people with Huntington disease to bath regularly. They frequently soil themselves and their clothes by spilling food and fluids when eating. They may also have some urinary incontinence as they have increased thirst and, therefore, drink more liquids. Because of their movements and balance problems many of them do not like to get into a bath or shower.

Generally a plastic chair placed in the shower makes it easier for the people with Huntington disease to concentrate on their bathing and not on balancing in the shower. This allows them to be independent for a longer time. If there is no shower, a kitchen chair placed in the bathroom or bedroom with a bucket of warm water, soap, cloths and towels placed nearby also makes it easier for them to continue with their own bathing for a longer time.

SOME OF THE EMOTIONAL AND PERSONALITY DIFFICULTIES ASSOCIATED WITH CARING FOR SOMEBODY WITH HUNTINGTON DISEASE

Of all the symptoms of Huntington disease the emotional and personality difficulties associated with the disease are the most challenging aspects for the caregivers and families to live with and to manage.

Listed below are some of the difficulties you may experience with him. He has no control over them as they are symptoms of the disease itself and not because he is trying to be difficult.

Making decisions

He cannot come to a decision. He finds it difficult to answer questions such as, “What clothes do you want to wear?” or “What do you want to eat?” It is easier if you give him a choice of options such as, “Do you want to wear shorts or jeans?” or “Do you want to have toast or porridge for breakfast?”

Apathy

Patients become unmotivated and disinterested in everything and everybody. They lose enthusiasm about previous interests. They seem to be totally indifferent to people around them and life in general. This behaviour is upsetting to family members who no longer see the active and energetic person they once knew. It can cause arguments when caregivers know the patient is physically capable of activities, but he just “won’t” do them. Sometimes this is because he cannot get started with an activity, but is willing to help or participate when somebody else reminds him how to start the activity.

Anxiety

Once a person has to stop a job that has become too difficult because of his symptoms, it usually results in a remarkable decline in symptoms. This anxiety is also often as a result of worrying about how his disease will progress, particularly if he remembers his parent having a difficult time with his/her

symptoms. It often helps if you can keep a positive attitude and reassure him that some of his future symptoms may be able to be helped by medication.

Depression

Many people with Huntington disease get depressed. This can be successfully treated by antidepressant medication so if you notice any of the following signs tell the doctor at the next clinic appointment:

- he is withdrawn;
- lacks interest in any of his previous hobbies;
- has no initiative,;
- has difficulty in concentrating;
- looks “down”;
- changes in sleep patterns such as having difficulty falling asleep, waking up very early in the morning or waking up several times during the night ;
- loss of appetite;
- increased irritability; and
- speaks about attempting suicide.

Fatigue

Fatigue can affect people dramatically, but it is often difficult for the caregivers to recognise it. One can notice it by his irritable behaviour and his walking, talking and swallowing may get worse. Fatigue often occurs because people with Huntington disease use a great amount of effort for simple activities such as walking and standing, and may get tired early in the day. He should be encouraged to have rest periods throughout the day if he is tired, particularly before he eats his meals so that he can swallow easier.

Irritability, anger and aggression

People with Huntington disease can be angry for many reasons. They may be angry because they have the disease in the family, losing a parent to the disease, putting their own children at risk, losing their ability to support their family, being

dependent on others for care and losing their ability to do normal daily activities.

There is often something that triggers this behaviour. It may be hunger, pain, inability to communicate, frustration because he is unable to do something, boredom, difficulty with interpersonal relationships, and in particular, minor, unexpected changes in routine. These can all bring on an irritable or aggressive outburst.

As people with Huntington disease are unable to control their emotions, and this together with frustration at not being able to be understood or not being able to do things independently, can make them have temper outbursts when anything upsets them. They might also be frightened as they are confused and do not understand what is happening around them if their routine is disturbed, they are in a new environment or are seeing new faces. These outbursts may take the form of shouting, swearing and insulting the caregiver. They may also be in the form of physically lashing out at the closest person who is mostly the caregiver.

Obsessive-compulsive disorder

The patient gets “stuck” on an activity like closing a door and goes round the house closing all the doors over and over again. Sometimes he cannot get off a topic and repeats his words over and over and cannot move onto another topic. He may also smoke one cigarette after another or, if he is unable to light a cigarette himself, will ask repeatedly for another cigarette.

Inflexibility

He wants things done immediately and in a particular way. He has no insight or consideration for anyone else’s workload or how they are feeling.

Sexual disorders

Some patients want and demand a very high level of sexual activity. Wives may be quite distressed or fearful of their husbands who can become aggressive if their sexual demands

are refused. Other patients may exhibit inappropriate sexual behaviour such as masturbation in public or fondling strangers or exposing themselves. It is important for the caregiver to ask to see the clinic doctor on her own without the patient so that she can discuss the problem with him or her as there is medication available for this type of symptom.

CHANGES IN THE THINKING PROCESSES

The person may be easily distracted, confused, uncooperative, angry and withdrawn. He often wants things done immediately or gets irritated when you do things for him to assist him. This often leads to shouting and threats from him. When you are trying your best to care for him this is very hurtful. Remember that the reason he is behaving this way is caused by Huntington disease. Under any circumstances when people are stressed they often take it out on those they love most so try not to take it personally and you are the one who is always around caring for him so you will be the who receives most of the negative behaviour.

People with Huntington disease think slower and take longer to answer questions. It also causes them to take longer doing things they usually did automatically and quickly such as dressing, eating or household tasks. Because they still want to be independent, don't take over and do it for them to save time as it often leads to irritation and feelings of helplessness.

They find it difficult to starting off with a task so if they don't seem to get going with their dressing it is often helpful if you just give them a 'jump start' by telling them what to do such as, "First take your pyjamas off and then put your shirt on". Or it may mean you need to take his pyjamas off and have his clothes nearby so that he can continue dressing by himself. Give very specific instructions such as, "Clear the table" is better understood if you say, "Take the dirty plates to the kitchen sink". If you notice that they are wearing clothes inside out or back to front it is helpful if you lay them out on the bed

exactly as they are to put them on and then instruct them to, “First put on your shirt and then your jersey”. When they have accomplished this you will need to follow up with, “Now put on your socks and then your shoes”. They may also have difficulty in choosing the correct clothes so it helps to lay them out for the person.

Because the person is often confused and does not know what is going on around him he becomes angry when he needs something and wants it immediately and you are unable to do it just then. When he is confused he does not know what to expect next which causes him to become even more confused and angry. The way in which this confusion can be relieved is to provide a very consistent daily routine which he can get accustomed to and know what to expect next. This will assist in avoiding irritation and outbursts of temper.

It helps if you constantly remind him throughout the day about what is going to happen next such as, “After you have washed and dressed we are going to have breakfast”. If there is going to have to be a change of routine such as attending a hospital appointment let him know the day before so that it is not unexpected and does not cause a disruption to his routine.

MANAGEMENT OF SOME OF THE EMOTIONAL AND PERSONALITY DIFFICULTIES

There are no easy answers to dealing with personality and behaviour changes in the person with Huntington disease, but there are some basic approaches which may be useful. Remember that you as the caregiver deal with the person on a daily basis and will be able to adapt these approaches to deal with the specific behavioural difficulties of your relative. Remember too, that, however much you want to care for him in the best possible way, there are some behaviours that are unacceptable and you will need to be very firm in making him aware that you will not tolerate them.

Daily routine

The person with Huntington disease becomes inflexible and stubborn and likes to have a set routine during the day, and, if this is not adhered to he becomes agitated and has temper outbursts. A routine of waking, washing, toileting, dressing, eating, watching TV, etc at the same time and in the same way every day provides the person with Huntington disease with a sense of security of knowing what to expect and that he has not been forgotten. This helps to minimise his short-term memory loss, obsessive thoughts, apathy and difficulty in carrying out routine tasks as he can anticipate activities and predict with almost certainty what is going to happen during the day.

For the patient who takes a long time with routine tasks such as dressing, bathing, etc the caregiver should tell him aloud what to do or begin the first step in a routine such as putting toothpaste on this/her toothbrush. He can then complete the remainder of the activity of brushing his teeth himself or be reminded all the time about the next movement he has to carry out.

Avoiding frustration and confrontation

When the caregiver notices the verbal or non-verbal signals that the person is upset or agitated it saves a great deal of anguish to herself if she gives him attention immediately to avoid it developing into a major temper outburst. He is unable to tolerate refusal or delay in his needs being met. This together with his communication difficulties, can make it very exhausting for the caregiver, but many of the outbursts can be anticipated and avoided by the caregiver defusing them by reminding him of his next routine activity or suggesting that he occupies himself by watching TV or some other diversion. Even if you cannot meet his needs immediately, by responding to his verbal and body language signals he will know that he has not been forgotten and that his needs will be taken care of.

Dealing with aggressive outbursts

If you know the person is irritable you should avoid arguments and threats and try and keep the environment as calm and routine as possible. However, when he does have an aggressive outburst, for your own safety, keep well clear of him. Leave the room if necessary. Don't try and explain, cajole or reason with him at this stage as it may irritate him even further. Try and work out for yourself what has caused his reaction and try and avoid it in the future.

Again, this is part of the disease, and not necessarily meant to be directed at you. However, it is important that when you accompany him to the clinic you tell the doctor about these outbursts.

Imposing limits

Most of the strategies of dealing with the behavioural difficulties of a person with Huntington disease require the caregiver to fit in with the person with the disease when possible. However, there are certain behaviours which should not be tolerated. They are violence and sexual harassment. This is particularly so when the other members of the family are children as they also have a right to a reasonable quality of life and their own needs to be met. Personal experience of many caregivers has been that they were surprised that when they laid down the law about behaviour which they would not tolerate under any circumstances the person with Huntington disease was able to accept the limits set and understand the reasons behind them.

GENERAL SAFETY PRECAUTIONS

If the person has balance difficulties he should not climb ladders or walk independently over rough territory to avoid falling.

He should not use sharp knives to avoid cutting himself, particularly if he has a lot of movements in his hands.

Patients should wear lace-up shoes with wide heels or running shoes to provide them with support. They should avoid highheels or sandals and other shoes that offer no support as it makes the patient far more prone to falling.

If his judgement is impaired he will be unaware of the danger of burns to clothing, ashtray fires or furniture fires. The movements make it unsafe to use and throw away matches and lighters. He should be told that he is only allowed to smoke outside or in a room with cement or tiled floors.



Figure 13

Patients often fall close to the toilet, bed or a chair on which they have been sitting. To prevent this they should be taught to walk to the toilet, bend over and put their hand onto the toilet seat for support and to steady themselves, and then turn around and sit down while still holding onto the toilet. The same should be done for sitting on a chair or bed. When he needs to stand up he should put both his hands on his knees, lean his body forwards slightly until his shoulders are over his knees and then stand up. He should wait for a while until he has gained his balance before walking.

He should be encouraged to take a walk for at least 20 minutes per day to maintain his strength and balance and to keep his heart and lungs healthy. At first this can be done on his own, but if his balance becomes difficult or there is a great deal of traffic and roads to cross, it should be done with a caregiver providing support under his arm (Figure 13). This is also necessary if traffic distracts the patient and causes him to fall as he is unable to concentrate on his walking. He might have difficulty with memory or concentration even though he can walk without difficulty, but, as he might forget to check the traffic before crossing the road, he should always be accompanied by his caregiver or a family member.

THE IMPORTANCE OF THE CAREGIVER TAKING CARE OF HERSELF

Caring for a person with Huntington disease is an enormous challenge, physically, psychologically and emotionally. There are new difficulties to face on a daily basis and, as each person varies so much in their symptoms, it is a case of trying different ways of dealing with each difficulty.

It is very difficult see a person who was once your husband who worked and supported you and your family deteriorating over many years. It is also hard to know that, no matter how hard you try and care for him to the best of your ability, it won't change the course of the disease and he will get steadily worse anyway.

This is why it is important for you to take care for yourself.

You have the opportunity of discussing your caregiving problems with one of the medical team at the clinic. If you do not want to discuss these problems in front of your husband, ask one of the staff to report to the doctor that you need to see him/her on your own. This will give you the opportunity of discussing any particular behavioural problems you are experiencing with him such as depression or sexual problems. Frequently these difficult behaviours can be controlled by medication. You should report to the doctor whether you are feeling depressed yourself.

As there are no respite or day centres for people with long-term disabilities it is important that you try and get as much help and support from your family members or neighbours to give you a bit of a break away from him for a few hours per day or per week. People with Huntington disease often respond well to others who assist for an hour or two and do not appear to have as many temper tantrums with them as they do with their caregivers. Remember most people take out their frustrations on those they love the most as they feel comfortable, safe and protected by them.

CONTACT DETAILS

For information on disability grants, grants-in-aid, school fees rebates and Medic Alert bracelets contact the social worker at 021-404-5546.

For assistance with any problems with regard to the patient's behaviour, medication, predictive testing or arranging clinic appointments contact the Genetic Nurses at 021-404-6235 or 021-406-6304.

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