

Living Life to the Fullest: Families Share their Ideas

A resource of strategies for caring for an individual with Huntington's

Created for families by families

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Please be advised that each person with HD is unique, with different and changing needs. Before using any of the suggestions contained in this booklet please consult your physician or relevant health professional before to be sure that it is safe and appropriate for the individual's care.

In the face of it all, first and foremost, you need to take care, not only for the person that you care so much about, but also for yourself.

Contents

Introduction	i
Strategies for the Physical Challenges of HD	1
Maintaining independence	1
Preventing falls and injury	2
Transfers and fall prevention.....	3
Stability and posture	4
Daily comforts.....	5
Mobility	5
Eating	6
Aspiration	11
Food storage.....	11
Oral care.....	12
Swallowing medication	13
Smoking.....	13
Showering.....	14
Dressing.....	16
Exercise.....	17
Tracking the physical HD progression	17
Strategies for the Cognitive Challenges of HD	18
Complex tasks.....	18
Getting started	19
Getting “Stuck”	19
Decision making.....	19
Attention.....	19
Visual-spatial deficit	19
Slow thinking, slow to respond.....	20
Memory and recall.....	20
Communication and conversation	21
Impatience.....	22
Lack of self-awareness and denial.....	23
Mental stimulation	23
Tracking the cognitive HD progression	23
Strategies for the Emotional Challenges of HD.....	24
Anger and emotional outbursts.....	24
Apathy and irritability	25
Resources	26

Introduction

The Huntington Society of Canada is a national network of volunteers and professionals united in the fight against HD since 1973. The Huntington Society of Canada aspires to a world free from Huntington disease. The Society maximizes the quality of life of people living with HD by delivering services, enables others to understand the disease; and furthers research to slow and to prevent Huntington disease.

The purpose for *Living life to the Fullest: Families Share their Ideas* is to provide insight into the nature of Huntington disease and to provide alternative ways of thinking about creative ways for individuals living with this disease to make life easier and for others to support individuals living with Huntington disease through the progression of the disease. This information is not meant to replace an individual's ability to choose for themselves or the need for individual assessment by an appropriate therapist: Physician (Family, Neurologist, and Psychiatrist), Neuropsychologist, Occupational Therapist, Physiotherapist, Speech-Language Therapist, Nutritionist, and Dietitian. These specialists, along with information pertaining to the specific individual will aid in the development of an appropriate care plan. The Huntington Society of Canada has also developed a number of other resources (e.g. *Physician's Guide to the Management of Huntington disease*, and the *Caregiver's Handbook for Advanced-Stage Huntington disease*) which may also provide valuable information into the care and support of individuals living with HD.

The nature of Huntington disease means that those living with will experience a wide range of changes in movement, emotional and thinking. These changes can affect multiple aspects of their participating in the world: *Activities of Daily Living*, *Instrumental Activities of Daily Living*. This handbook is not meant to provide inclusive suggestions for ideas that will help individuals living with HD as each person is unique with individual preferences, desires and triggers. It is most important to know the individual who you are supporting well: talking with the individual or their families, to learn about their unique qualities. This information will inform your ideas on how to best support. We have included some ideas that may work to encourage eating, bathing, or reduce frustration or aggression. We encourage readers to share their solutions in how to make life easier with the Huntington Society of Canada to potentially be incorporated into future editions of this book.

Strategies for the Physical Challenges of HD

Challenge: Maintaining independence

Strategy: Baby monitor

Placing a baby monitor in a room can provide a sense of security in case of need and/or assistance while still maintaining privacy.

Challenge: Preventing falls and injury

Strategy: Hospital bed

A hospital bed with rails can be used to prevent falls. The bed rails provide security and the ability to raise and lower the bed provides more lateral mobility and an increased ability for personal grooming. Padding around the railing may be helpful to prevent injury.

Strategy: Safety frame and grab bar

A safety frame and grab bar around the toilet provides additional support as physical strength lessens. It might also be helpful to use a raised toilet seat.



Challenge: Preventing falls and injury

Strategy: Hospital bed with legs removed and soft carpet

A hospital bed with the legs removed, placed on a soft carpet, places the bed closer to the ground reducing the distance in case of a fall.

Strategy: Hip pads

Hip pads are available to strap around hips to protect against fractures.

Strategy: Helmet

Wearing a helmet can prevent injury once falling becomes a concern.

Strategy: Walker

A walker can help with stabilization when walking. Consult an Occupational Therapist or Physiotherapist for the most appropriate type and fit of walker.

Strategy: Physical space and footwear

Reduce clutter and loose rugs in the home. Wear supportive, non-slip footwear.

Strategy: Physical health

Have eyesight and hearing checked regularly (they are important for balance). Do not walk while wearing reading glasses. Always wear hearing aids. Have medications evaluated (some cause dizziness and weakness which increases risk of falls). Have strength and balance tested regularly.

Regular health checkups are important for everyone. These checkups should include, but are not limited to: Eyesight, hearing, medications, strength and balance. Always wear hearing aids, and do not wear reading glasses when walking.

Challenge: Transfers and fall prevention

Strategy: Transfer belt

A transfer belt is a belt with handles that can be worn by a person who needs help with transfer. The transfer belt enables the caregiver to help the individual transfer from one chair to another (e.g., Love seat to wheel chair, wheel chair to toilet, etc.) and to shift positions. When used properly, the transfer belt helps to lessen the strain on the caregiver's back and leaves the individual with a greater feeling of safety. Instruction in to the proper use of the belt is important to prevent injury for everyone.



Strategy: Electric lift and rolling table

An electric lift can be helpful for moving an individual from bed to chair, to toilet, etc., when mobility becomes very difficult. Tracks are installed on the ceiling, or free standing options are available. Training in the proper use of this lift is important to ensure the safety of the person with HD and the caregiver.



Challenge: Stability and posture

Strategy: Foam wedge

A foam wedge helps with stability and maintaining proper posture. A foam wedge can be used under the seat of the wheelchair. Speak to the Occupational Therapist or Physiotherapist who prescribed the wheelchair to ensure that the size and position of the wedge assist in posture. If the wedge is not placed correctly, the sitting balance and muscle tone could be made worse.



Strategy: One-way slide mat

Try a one-way slide mat placed under an individual where they like to sit (eg. Loveseat, favourite chair, etc.). In the later stages of the disease, individuals may have more difficulty in maintaining their balance, which affects their posture and they may need assistance to re-position themselves. A one-way sliding mat allows the caregiver to maneuver the mat to easily readjust the individual as needed.



Challenge: Daily comforts

Strategy: Reclining leather love seat

Reclining leather love seats are a comfortable solution when individuals spend more time in the sitting position. Large controls can be easy to use. The love seat allows family members to sit with the individual and the leather surface is easy to clean.

Strategy: Large and flat TV remote

Buy a large and flat TV remote control (can be found at drug stores and stores that sell assistive devices). This makes changing channels easier, allows more independence in watching TV, and makes watching TV more enjoyable.

Strategy: Cordless headphones

Buy a pair of cordless headphones so that the person with HD can listen to TV without distraction. Once chorea becomes so great that the movement of the head causes problems with keeping headphones on head, attach the headphones to the liner of a hardhat.

Challenge: Mobility

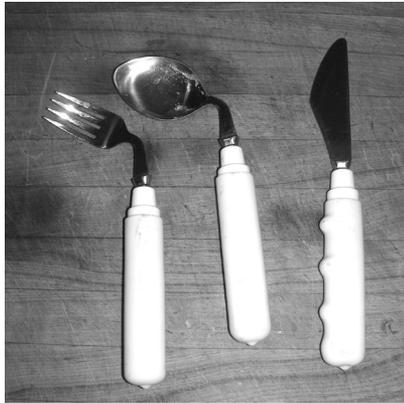
Strategy: Wheelchairs

A wheelchair should be fitted to meet the needs of the individual – A wheelchair lower to the ground works well as family members can use their feet for mobility. Later in the progression other changes should be assessed as needed such as a more comfortable chair with footrests. There are some wheelchairs that have been designed with the specific needs of people with HD – check with an Occupational Therapist or Physiotherapist for these specific pieces of equipment. The trick is to find a balance between comfort and usefulness.

Challenge: Eating

Strategy: Shaped utensils

A large-handed set of utensils with a shaped fork and spoon can be used if an individual has trouble feeding him/herself. An Occupational Therapist can provide an assessment, inform you of the different kinds of cutlery available, and help to select the ones that will help the most.



Strategy: Eating stands

Using a stand to place the eating trays on during mealtime provides convenience as it can aid both the individual and the caregiver.



Challenge: Eating

Assessments by a speech language therapist and/or nutritionist are important to determine the proper food consistency and feeding techniques.

Strategy: Large-based mug and straw

A wide base mug makes it easier to set the mug down and provides more stability.



Strategy: Thicken Up

The product “Thicken Up” can be added to thinner liquids and foods. This product can help with swallowing problems, limiting the risk of choking issues.



Challenge: Eating

Assessments by a speech language therapist and/or nutritionist are important to determine the proper food consistency and feeding techniques.

Strategy: Thicken liquids (soups, drinks, sauces)

There are many ways to thicken soups, drinks and sauces often already found in your kitchen cupboard:

- Use enriched cereal or rice cereal
 - Already thick juices such as tomato and pineapple
 - Blend fruit juices with fresh or canned fruit
 - Milkshakes or eggnog
 - Use gelatin, milkshake thickener, or instant pudding
 - Use instant mashed potato, baby rice or flaked rice
-

Strategy: Feeding techniques

When assisting someone to eat remain at eye level while feeding. Allow enough time to swallow and check for a complete swallow. Make sure the bites are not too big (e.g. offer only 1 teaspoon at a time, or even less). Allow the persons lips to close completely around the teaspoon and apply a slight downward pressure on the tongue when removing the spoon from the mouth. For some people with HD it is helpful to use only one texture or fluid consistency per mouthful. Ensure a complete swallow before offering a drink. Check mouth once meal is finished and clear away any remaining food between the gums and cheeks.

Strategy: Chin to chest

Encourage the person to bring their chin to their chest when they are ready to swallow.

Strategy: Ice water before and during meal

Beginning a meal with a drink of ice water (lots of ice), this prepares the mouth to swallow. Allow a drink of the ice water throughout the meal, after every three mouthfuls of food (only once food is completely swallowed and cleared from mouth).

Challenge: Eating

Assessments by a speech language therapist and/or nutritionist are important to determine the proper food consistency and feeding techniques.

Strategy: Food temperature

Hot or cold items appear to be easier to swallow than room temperature items. Make sure food is not so hot that they burn the mouth.

Strategy: Use a teaspoon

Use a teaspoon for eating to reduce the amount of food in a mouthful, slowing down the eating process and allowing for more proper chewing.

Strategy: Keeping food moist

Keep food moist – use sauces, gravy, and soups, such as cream of mushroom.

Strategy: Encourage coughing

Encourage coughing during a meal; it is the natural way for the body to prevent food and beverages from going into the lungs.

Strategy: Calm and quiet

Feed in a quiet area to reduce distractions (distractions increase swallowing difficulties). Speak calmly and quietly and encourage the individual.

Strategy: Wrist weights

Wearing wrist weights while eating helps to slow the chorea and make feeding oneself easier.

Challenge: Eating

Assessments by a speech language therapist and/or nutritionist are important to determine the proper food consistency and feeding techniques.

Strategy: Food selections from all food groups

Breads and cereals group – soft breads with crusts removed; bread buttered on both sides; rice (well cooked), macaroni, pasta, preferably with sauces or cream; mashed or soft-boiled potatoes with added milk and butter; crushed crackers in soup

Fruit and vegetables group – ripe fruit, canned fruit, or cooked fruit; remove seeds and skin; cut fresh fruit into small pieces; add fruit to milkshakes, ice cream, puddings, etc.; remove skin and seeds from vegetables and cook; use vegetables in stews and casseroles; chop vegetables or put in blender for a short time

Meat and meat substitutes group – select tender cuts, mince meat; serve with sauces and gravies; cut into small pieces; use moist cooking methods such as simmering, poaching, stewing; prepare moist dishes such as pot roasts, meat loaf, casserole, chowder; use eggs in omelettes, scrambled, poached, soft boiled, soufflés, custards, puddings, French toast, crepes and pancakes

Dairy group – use milk products in mixes, sauces and soups; incorporate variety such as yogurt, ice cream, sour cream; serve yogurt at the end of a meal (cleanses the mouth and feels refreshing)

Strategy: Control saliva levels using food

Sometimes the mouth produces too much or too little saliva for swallowing. The amount of saliva produced is reactive to the types of food we eat. You can serve sour food (e.g., lemon, ice, or carbonated drinks) to stimulate saliva. Sweet tasting food (e.g., juice from canned fruit) can decrease the amount of saliva produced.

Strategy: “dry swallow” or “double swallow”

To prevent choking, encourage the person “dry swallow” or “double swallow” between bites, to ensure all of the food has been swallowed.

Strategy: Protein shakes or Carnation Instant Breakfast

Protein shakes or Carnation Instant Breakfast are a good alternative to Boost and Ensure.

Challenge: Eating

Assessments by a speech language therapist and/or nutritionist are important to determine the proper food consistency and feeding techniques.

Strategy: Use of smells to stimulate appetite

Food scented candles such as apple, pumpkin, and vanilla, can stimulate the appetite.

Challenge: Aspiration

Strategy: More frequent meals of shorter duration

Feed more frequent meals of a shorter duration, reducing feeding time to 30 minutes. After 30 minutes the risk of aspiration increases due to exhaustion. Reassure the individual that they will receive a snack in an hour or so once they have rested.

Strategy: Remain sitting after a meal

It might be necessary to encourage the person to remain sitting up for 45 minutes after they have eaten as there may be food particles remaining in their mouth that could cause aspiration.

Challenge: Food storage

Strategy: Food storage

To store leftovers in the fridge, Try using only two sizes of square containers that use the same size lids. You can label the container with its contents using masking tape., and double back the masking tape at one end to make it easy to remove. This idea is helpful when storing leftovers in the fridge. Since containers are all the same shape they stack easily. The labels make it easy to know at a glance what is in the containers. Since only two sizes are used, and both use the same size lid, finding the lids that fit is easy.

Challenge: Oral care

Regular dentist consultations and thorough dental hygiene are important.

Strategy: Fluoride gel

As brushing teeth becomes more difficult for an individual, try using fluoride gel twice a week to supplement the process.

Strategy: Biotène dry mouth toothpaste and child's tooth brush

When brushing teeth and spitting after brushing becomes difficult for an individual, try using a smaller toothbrush and a dry mouth toothpaste to prevent saliva build-up.

Strategy: Biotène mouthwash and applicator

The applicator allows the caregiver to apply the mouthwash to an individual's mouth to freshen the mouth.

Strategy: Moisturizer for dry lips

An individual is encouraged to switch from lip balm or chapstick to a moisturizer that will not dry out lips themselves. Muko, Oral Balance and petroleum jelly have been suggested by a swallowing specialist.

Strategy: Mouth light

Use a mouth light to examine the mouth for infections (bleeding gums, etc.) or food debris.

Strategy: Toothbrush soaked in mouthwash

Remove food and debris with swabs and/or soft toothbrush soaked in mouthwash. Use only small amounts of mouthwash to avoid aspiration. Clean teeth, cheek surfaces and surface of tongue and ensure you get in between lips and teeth and remove any sticky dry saliva.

Strategy: Electric toothbrush

Using an electric toothbrush can make oral care easier.

Challenge: Swallowing medication

Strategy: Pill crusher

A pill crusher can be used to crush daily medication. Crushing the pills limits choking hazards and allows the pills to be added to the food pump if necessary. Check with a pharmacist or doctor before crushing as some pills are time released and should never be crushed.

Strategy: Form of medications

Medications in the form of capsules or sugarcoated as these are easier to swallow. If too difficult to swallow, then request pills in pill form, crush them, and add them to food, if appropriate.

Challenge: Smoking

Strategy: Smoking cessation using nicotine inhalers

The nicotine inhaler allows to mimic the hand-to-mouth motions of smoking. However, it is important that you do not inhale into the lungs since the nicotine is absorbed through the lining in the mouth and throat. You can wear the inhaler (shaped like an old cigarette holder) with a string around the neck. Slowly, over a period of several weeks, you can reduce the nicotine intake. It is important to discuss this option with your physician and/or pharmacist first.

Strategy: Smoking robot

A smoking robot is a hands-free smoking aid. A cigarette holder is attached to the base of the ashtray and a long tube connects the cigarette to a mouthpiece through which the individual smokes. This device is helpful once chorea makes holding a cigarette difficult and unsafe.



Strategy: Smoking blanket/smoking apron

The smoking blanket/apron is made of no-flame fabric to prevent cigarette burn holes. When chorea worsens and smoking safety becomes a concern, a smoking blanket/apron may be considered.



Challenge: Showering

Strategy: Tilting shower wheelchair

A shower specific tilting wheelchair with a belt and a hole in the seat of the chair can be used when standing in the shower or sitting in the bath is too trying for an individual. The chair is secure and provides a feeling of safety.



Strategy: Hand spray for shower

The hand spray can be used to assist in showering when the individual is in the wheelchair.



Strategy: Shower stall with seat and grab bar

Having a shower stall with a seat and grab bar can provide more safety and stability in the shower.

Challenge: Showering

Strategy: Break the process into smaller steps, keep the person informed

Showering can be an anxiety provoking situation. To reduce anxiety, let the person know what's going on, what's coming next, and how much longer it will be. Give them a “heads up” before doing anything, use the same order to help them wash up, wait for their responses and respect their preferences. Wait until both of you are comfortable before turning on the water.

Example:

“I’ll be back in five minutes; it’s almost time to shower”

“Ok, we’ve got towels, soap and shampoo”

“Ok, we’re safe, let’s go!”

“Let’s shampoo your hair”

“Tilt your head back; I’ll rinse your hair”

“Now let’s wash your face”

“Let’s get in your ears”

“Good, we’re halfway done”

And so on, until . . . “Finished! Let’s get dry!”

Strategy: Protective garments for showering

There are high-quality protective garments available for caregivers to wear while helping the individual, including a cap to keep their hair dry and booties to slip on over their shoes.



Challenge: Dressing

Strategy: Bras without fasteners

For women, get bras without fasteners. Elita is the preferred brand: they are cotton and pull on and off which makes it easier to get dressed.

Strategy: Shoe-lace free

Try shoes with zippers, such as Natural Support zipper shoes by Dr. Scholl's; curly shoe laces; or Velcro shoes.

Strategy: Underwear suggestions

Microfiber underwear may help with itchiness. Wearing underwear and socks inside out, with the seams away from the body, is more comfortable for anyone who spends a lot of time sitting or lying or who has poor muscle tone.

Strategy: Eye-glass protection

A strap that hooks onto the arms of your glasses and goes around the back of the head will help to hold the glasses in place, but should the glasses fall off, they will not fall on the floor and be broken.



Challenge: Exercise

Strategy: Exercise

Try having the person participate in physical exercise such as aqua-therapy, rehab walking, yoga, chair exercises, physiotherapy, or anything else the person is capable of doing. Research has shown that 30 minutes of exercise 3-4 times a week may be beneficial. Doing it in a group adds the benefit of socialization, which is extremely important and has recently been shown to help a person live longer.

Challenge: Tracking the physical HD progression

Strategy: Regular check-ups

Have regular Speech and Language Pathologist, Occupational Therapist, Neurologist, Dietician, Speech-Language Therapist, and other appropriate specialists assessments to track the physical progression of HD and to have adequate supports in place at the appropriate times. Annual check ups with family doctors can monitor overall health.

Strategies for the Cognitive Challenges of HD

Challenge: Complex tasks

Strategy: Talking through tasks or verbal cueing

Break each task into its sequence of smaller components and talk through each small step. State simply and concisely what is to be done next, and then assist in the completion of each step one-at-a-time. Allow plenty of time for each task. Be patient. Talking through tasks does not work when you are racing the clock.

Talking through the task helps to make complex tasks more manageable for the receiver of care and for the caregiver. It helps the care receiver to maintain focus. It also provides opportunities for personal choice, reinforcement of safe behaviours and giving commendation.

This technique is good for such tasks as transfers from bed to wheel chair, wheel chair to recliner, or vice versa; toiletry and bathing, dressing, and eating. When eating varied textures, cueing helps to make safe transitions and ensure the mouth is clear and ready to receive the next mouthful. It also provides opportunity for making choices of what will be eaten next, or what will be worn today.

Strategy: Breaking down the task

As learning new tasks and sequencing complex learned tasks becomes more difficult, try breaking the complex information into simple steps, write down the steps, encourage practice, and allow extra time to learn.

Strategy: Planning, sequencing, prioritizing

To make complex tasks and daily activities more manageable:

- Structure the task
- Organize the information numerically, spatially, etc.
- Maintain routines
- Write down activities

Challenge: Getting started

Strategy: Gently guide and offer help

Gently guide the person, offer help to get started, maintain a daily routine. Help others to understand that a lack of initiative is a common symptom of HD and not a sign of laziness.

Challenge: Getting “stuck”

Strategy: Shift focus

If a person is fixated on a task/topic gently use humor to “unstuck”, establish a time limit, use distraction.

Challenge: Decision making

Strategy: Limit choices, keep it simple

Offer limited choices, use short sentences, use closed questions (eg. yes/no responses), avoid open-ended options, allow choice and return to the question later if necessary.

Challenge: Attention

Strategy: One thing at a time and avoid distraction

Assign only one task at a time, provide a quiet environment, and maintain eye contact.

Challenge: Visual-spatial deficit

Strategy: Orient to a new neighbourhood

Orient to a new neighbourhood: write directions, use signs, avoid independent travel in new areas.

Challenge: Slowed thinking, slow to respond

Strategy: Allow extra time

Allow the person enough time to answer or react, be patient during long pauses, maintain focus on the person, and limit distractions in the environment.

Strategy: Wait! No response does not mean no

Wait, tolerate the silence, give more time than bearable – this can be very difficult and frustrating, but keep waiting! Remember that no answer doesn't mean "no"

Challenge: Memory and recall

Strategy: Offer cues, hints, and alternatives

Provide cues, hints, missing words. Avoid open-ended questions, offer choice of two alternatives.

Strategy: Calendar, schedule, "to do" lists

Use "to do" lists or written reminders. Maintain a daily routine, and establish a schedule and calendar that is posted in the individual's room.

Strategy: Gradual refinement of the question

Ask an open question, then wait . . .

Ask a multiple choice question, then wait . . .

Ask a yes/no question, then wait . . .

If still no response, excuse yourself graciously, then . . .

Return in a moment or two and start over!

Challenge: Communication and conversation

Strategy: Making the message clear

Speak slowly, repeat or rephrase the message, simplify the message, offer cues, try to gain topic knowledge, spell part of the message, use yes/no questions, refocus the person on the topic.

Challenge: Communication and conversation - perseverance

Strategy: Reduce number of topics, introduce transitions

Perseveration is the continuation or repetition of a topic or sentence and the inability to modify that behaviour after it has become inappropriate.

To reduce perseveration, reduce the number of times you change topics during a conversation, introduce a topic change by saying “we are changing subjects now”, allow some time to pass before introducing a new topic, and let the person know when perseveration is occurring.

Challenge: Communication and conversation – sharing stories

Strategy: Life book/memory book

Create a life book/memory book – the book can contain items such as stories, cards, pictures, and is essentially a scrap-book of their life. This book allows the person to share his/her life story with new people, as well as provides topics of conversation for family and friends. Life books/memory books also assist in conversation as verbal communication weakens.

Strategy: Guest book to record visitors, activities, etc.

Keeping a guest book or journal to record visitors, activities, etc. allows you to look over whom the person with HD has seen and what they have done since your last visit, providing topics of conversation.

Challenge: Communication and conversation – non-verbal

Strategy: Keep the person informed, recognize non-verbal cues

Keep the person informed; remember that even if a person may not speak, he/she can still understand you. Recognize and use gestures and facial expressions as communication tools. Be innovative and perceptive, establish a routine for care, inform others of the strategies.

Challenge: Communication and conversation

Strategy: Communication board, book or flash card set

Creating a communications board, book or flash cards may be helpful if communicating orally becomes difficult. This board, book or flash card set would have one square, page, or card designated to a certain daily activity or emotion, and would consist of a picture and perhaps one word underneath of the picture; for example, a smiling face with the word “happy”, a toilet with the word “bathroom”, music notes with the word “radio”, then when the person wants to communicate how they are feeling, that they need to use the toilet, or that they want to listen to the radio, they would just need to point to the picture. The format and content of these boards/books/flash cards would be created based on the individual’s interests, needs and abilities. It may be a good idea to begin creating and using these tools while the individual can still speak so that they have time to become accustomed to using this aid. Using pictures from the aid to create a schedule may also be helpful.

Challenge: Impatience

Strategy: Give a timeline and stick to it

Avoid saying “no” or “wait”. Caregivers should explain to the person with HD when they will be able to respond then they should stick to it. Remember that a minute means 60 seconds. It’s best to fulfill a request right away, but if not possible, than it’s better to overestimate the time needed and complete a task earlier rather than to underestimate and be late

Challenge: Lack of self-awareness and denial

Strategy: Acceptance

Accept the physiological lack of self-awareness as one possible symptom of HD. Evaluate why (and if) it needs to be addressed, and ask your loved one to choose incentives for compliance. Depending upon the issue, consider involving your loved one in a written, formal agreement. Psychological denial can improve with time, and with brief, simple and infrequent reminders of the issue and a solution.

Challenge: Mental stimulation

Strategy: Daily mental exercise

Spend time doing mental exercises everyday through a variety of activities: cards, crosswords, puzzles, cribbage, dominoes, brain teasers, blocks, and anything else that make the brain work. These exercises can help to regenerate brain cells and can delay the impact of the progression of the disease.

Challenge: Tracking the cognitive HD progression

Strategy: Notebook to record changes

Keep a notebook to record the cognitive changes and any questions for the doctors.

Strategies for the Emotional Challenges of HD

Challenge: Anger and emotional outbursts

Strategy: Don't take it personally, recognize the validity of their feelings

Don't take the anger personally. Try to figure out the cause and acknowledge and accept the person's anger and frustration as valid feelings. Explain understanding and acceptance of any frustration and anger.

Strategy: Explain what is not acceptable without blame or punishment

Provide clear, direct feedback as to the outbursts effects on others. Provide firm encouragement to accept responsibility for the behaviour, especially towards others. If necessary, review the person's sense of responsibility to care for the caregiver. Express your limits and be firm about what is not acceptable without blaming or punishing.

Strategy: Redirect

Redirect from the source of anger, avoid confrontation or ultimatum, keep self calm, safety is a priority.

Strategy: Highlight positive exceptions

Observe, gather and share information about times when the challenging behaviour does not occur, about the places and environments in which the person does in fact experience a good time, and about the people with whom such good times are possible. If you know what determines a "good time" you can try to ensure these conditions are given as often and consistently as possible.

Strategy: Identify triggers

Identify "triggers" of outbursts and find ways to avoid these triggers in the future to prevent future outbursts. Share this knowledge with others caring for the individual.

Challenge: Anger and emotional outbursts

Strategy: Increase predictability

Try to understand feelings of frustration and work towards increasing predictability from moment to moment with sequences and similarity, creating routine.

Challenge: Apathy and irritability

Strategy: Remember they are the “flight” and “fight” response

Apathy and irritability are expressions of our basic “flight” or “fight” responses. Apathy is “flight” – withdrawal, going along with things, ignoring. Irritability is “fight” – arguing, anger, aggression. These responses occur because of stressors, so to overcome them, find out what the stressor is and avoid stressful situations by: going slow, taking one thing at a time, responding timely and wait, say what’s coming up next, offer choices, have a daily routine (and stick to it), and no surprises. Anticipate to prevent problems.

Strategy: No surprises

Surprises cause anxiety, which cause people to react by withdrawing (apathy) or fighting (irritability). Reduce surprises by completing tasks in the same sequence or order, sticking to a daily routine, going slower but not slow, previewing and reviewing, offering a play-by-play description, acknowledging clear milestones, and indicating a clear beginning and end to each activity and task.

Resources

This book was written by families for families. Families who are living with HD and wanting to share some of their ideas of how to best support their loved ones and themselves. There are several professionals throughout the world who are dedicated to making life better for those affected by HD. Please contact your local/national HD organization to receive specific referrals for specialists in your area or professionals who would be happy to speak with you over the phone.

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“The Safe Living Guide”

(<http://www.phac-aspc.gc.ca/seniors-aines/pubs/safeline/index.htm>)

“Go For It: A Guide to Choosing and Using Assistive Devices”

(available online at the Health Canada website http://www.phac-aspc-gc.ca/seniors-aines/pubs/go_for_it/goforit_toc_e.htm)

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