MND Factsheet 15A
Care at Home

Last Updated 23/11/15

Common Causes of Concern

Caring at home for someone who has MND can sometimes give rise to concerns from problems arising indirectly from secondary effects of the disease. For example, if someone becomes limited in their arm movements they might require help with washing and personal care, more so if they are also unable to stand because of weakness in their legs.

The following hints and advice are adapted from the "Help the Hospices" manual "Caring for Carers." (See Further Information at the end).

Washing and personal care

As someone gets weaker they might need more help with washing and bathing. This may be very difficult for them emotionally as it signifies a loss of independence and privacy.

Helping someone wash is relatively straight forward, helping them in and out of a bath is more difficult than people think. Seek help rather than risk a damaged back, as back pain is not easily or quickly cured. Bear in mind you may need to call on professional help or special equipment for bathing.

Extra help

If someone needs more help than you can provide, extra help can be arranged either by Social Work "Home Carers" or by other agencies who, depending on need, can visit up to seven days a week. As someone becomes more ill, more specialised help may be needed. Ask your GP or MND Care Team Member for advice.

Equipment

Some simple equipment may make things much easier for both the carers and the person with MND, e.g. a bath seat, bath board or sometimes an electric bath hoist. Ask your District Nurse or OT about what is available and what might help you. Whoever supplies the equipment should also instruct you on how to use the aids safely before you start to use them.

Skin care

If someone is ill, immobile, or spending a long time in bed or a chair, they may find their skin becomes tender or dry. Damaged skin is a potential site of infection and pressure sores can be very painful.

- Check the person's skin everyday. Look at pressure points carefully. These are likely to be on the spine, elbows, hips, heels and ears.
- Keep bed sheets dry and as free of wrinkles as possible.
- Use a mild soap.
- Pat dry with a towel - do not rub.
- Use moisturiser on pressure points and hard skin.
- Encourage a change in position every couple of hours, if possible.

When to seek help

If skin becomes red or sore, tell your District Nurse or GP as soon as possible.

Mouth care

Mouth care is an important part of daily care especially when someone is very ill. Good care prevents mouth sores and, because the person feels more comfortable, may improve appetite. See Factsheet 36 "Oral Health."

How to help

- Do help with regular denture or teeth cleaning (using a soft toothbrush).
- Encourage plenty of fluid intake, or sucking ice cubes, gum or pineapple to keep the mouth moist.

- Apply Vaseline jelly or lip-balm to the lips.

What to look out for

Look out for:

- white patchy areas on the mouth
- red, shiny tongue
- cracks in the corners of the mouth as they may require special treatment

When to get help

Report any problems to your nurse or doctor as soon as you notice them so they do not have time to develop.

Mobility

As people become less well, they may find it becomes more difficult to move around. This may be because of weakness, fatigue, pain, breathlessness or a combination of things that just make it seem too much effort.

While rest is important, it is also important to encourage someone with MND to continue to move around independently as much as possible in as safe a way as possible.

Keeping mobile

Someone with mobility problems should change position frequently and take short walks if possible. Even walking to the lavatory and back is good exercise.

- A simple walking aid, such as a stick or frame, may help to maintain mobility and improve confidence. It is much safer to use an aid than to clutch on to furniture or people. A physiotherapist can advise on what aids are available and best suited to your needs.
- It is much easier to get up and down from a firm base than from a very soft one. Try to ensure that the bed has a firm base and the mattress does not sag and that a firm and comfortable armchair is available (neither the bed nor the chair should be too low or too soft). Better still is a "Riser recliner" type of armchair and a motorised bed.

See Factsheets 5A, Assistive Equipment, 5B Maintaining Mobility, 5C Getting the Best From Physiotherapy and 5D Aids to Maintain Mobility.

Keeping safe

- Make sure clothing is not hindering mobility or safety. Clothing needs to be loose and comfortable, but not too long or it may cause someone to trip. This is a common problem with nightwear and dressing gowns.
- Footwear needs to be comfortable but secure. Avoid "sloppy" footwear without backs. A slipper that cradles the whole foot is much safer than a mule type.
- Make sure that the soles of shoes or slippers are not shiny or slippery.

Avoid creating hazards

- Try to keep things tidy and uncluttered.
- Make sure doorways are not blocked by things jutting out.
- Make sure the floor is clear of hazards.
- Remove flimsy items that could be easily knocked over.
- Make sure the flooring is secured, e.g. no loose rugs to trip over, no carpet edges or tiles lifting.

What to do if someone falls

- Try not to panic.
- Don't rush to get them up quickly; you may injure them or yourself.
- Try to stay calm and reassuring.
- Let them sit on the floor for a few minutes to get their breath and see if they have hurt themselves.
- Don't try to stop a fall by "catching" the person. Instead, ease them gently to the floor if you can.

If the person is unhurt and has no pain, and is able to get up on their own, then let them do so. Putting a firm chair next to them may help, or encourage them to move across the floor on their bottom to a solid armchair.

When to get help

If your friend/relative appears hurt or in pain, or is too frail to get up without assistance, phone 999 and ask for the ambulance service. They will know what to do.

Keep the person as warm and as comfortable as possible on the floor while waiting.

Helping to move someone

Avoid the temptation to help someone to do things they can manage by themselves. It is safer for them to be as independent as possible, even if you could help them do it more quickly. If a manoeuvre seems very difficult, or you are in any doubt, don't attempt it alone; seek help.

- Ask a professional, e.g. physiotherapist or District Nurse, for tips on how to move someone; some of the techniques are not obvious until you have seen them demonstrated!
- Using a good technique will often enable someone to retain their independence for as long as possible.
- Make sure you and the person being moved both know what you are trying to do, and how you will go about it, before you start.

To stand from sitting

- Bring the person's bottom forward to the front of the chair/bed/lavatory.
- Place their hands firmly on arms of chair. If there are no arms, place their hands on the edge of the seat.
- Tuck their feet well back under them, a little way apart.
- Lean forward from hips (nose over toes!).
- Push through arms to stand. If further help is needed, assist by giving gentle forward pressure on the back, between the shoulders. Say "ready, steady, up," so you work together.
- If a walking aid is used, they should now take hold of it.
- Make sure their knees are straight and they are well balanced before they start to move or walk away.

This sequence can be reversed to sit from standing.

To help turn someone in bed

You might need to do this to change the lower bed-sheet when someone is bed-bound or to place towels under them when giving a bed-bath.

1. Fold down tight or heavy bedclothes (you can keep the person covered with a small light blanket).
2. If possible have only 1 pillow whilst moving.
3. Ask the person to bend both knees and to put their feet flat on the bed. (You can do this gently for them, one at a time, if they are unable to do it for themselves.)
4. You then stand at the side of the bed they are going to face.
5. Bring their far arm towards you across their body.
6. Facing the person, place one hand behind their shoulder and one behind their hip.
7. Ask them to roll towards you if they can, if not you can gently roll them towards you.
8. Use pillows behind their back to support them, if necessary, and ensure they are comfortable.

There are lots of ways to turn someone in bed. Ask the District Nurse to show you the best techniques for your situation.

Special equipment

It is much easier to nurse someone in a hospital-type bed than a domestic one. Some other specialist equipment such as a hoist may also be helpful. Your District Nurse and other professionals can usually arrange the supply of beds and related aids and show you how to use them.

Diet

As with any illness people with MND can "go off their food" and might not eat what is provided. There can be a number of possible reasons for this;

- The person might not be drinking enough,
- The person might not be burning up as much energy as before so needs less food intake,

- Some medications, particularly painkillers, some anti-sickness drugs, and iron supplements, might be stopping them from feeling hungry, or
- They may have swallowing difficulties.
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Whatever the cause, it may be that several small portions of food offered several times a day are more likely to be eaten than the standard three large meals per day. If swallowing difficulties are the problem see our Factsheet 34 'Adapting to Swallowing Problems.'

Meal supplements

Liquid supplements provide extra nutrition and can be used as a meal replacement or taken between meals to increase intake. They are available on prescription from your GP. Ensure, Enlive, Fortisip and Fortijuice are just some of the most popular brands.

How you can help?

- Encourage the person to sit as upright as possible when they are eating or drinking.
- Ensure meals are taken in a relaxed environment.
- Alcohol can act as an appetite stimulant, e.g. a small sherry 15 minutes before a meal.
- Use a small plate.
- Offer small snacks/meals frequently.
- If possible prepare what is wanted, only when it is wanted.

Constipation

Constipation means infrequent, difficult passage of small, hard stools. People vary in what they consider a normal pattern, but it is important for us all to empty our bowels regularly, even if we are not eating much. Constipation causes many problems such as discomfort, nausea, vomiting, reduced appetite and, in severe cases, confusion and bowel obstruction.

What can be done?

Usually the problem will be solved by taking enough oral laxatives. However sometimes suppositories or enemas may be needed. The GP will prescribe them and the District Nurse will administer them and then help monitor the situation.

What can you do to help?

- If you can, keep an eye on bowel habit in terms of frequency of actions and consistency and amount of motion.
- Give 'high fibre' foods such as cereals, vegetables, ripe fruit and dried fruit or fruit juice drinks.
- Ensure as much fluid is taken as possible.
- Ensure laxatives are taken, if recommended, and monitor their effect.

Remember that everybody is different and some will need different amounts of laxatives to overcome constipation. The dose can be varied as long as it does not cause problems of colic or diarrhoea.

When to call for help

- If bowels have not moved for 2 or 3 days,
- If there is any discomfort, or other symptoms of constipation such as bloating,
- if you are not sure what to do,

Severe constipation can sometimes cause "overflow diarrhoea," that is very watery stools around a very hard stool. If this happens, contact your doctor or District Nurse.

Incontinence

Incontinence is when someone loses control of their bladder and/bowels, this is different from when someone with MND is unable to push with their tummy muscles and so cannot go to the toilet effectively when they want to, and later has a small accident. It is important to talk to your doctor or nurse about this as there are several things that can be done to help. If it cannot be prevented, you might need help to cope with the problem.

Possible causes

- Loss of mobility. It may be that the patient is unable to move quickly enough to get to the toilet on time. A commode by the bed may solve the problem.

- Infection; bladder infections can cause a feeling of urgency and a frequent need to pass urine. These infections can be treated with antibiotics. Some people find a glass or two of cranberry juice each day helps acidify the urine and reduces the chances of recurring infections.

What you can do

- Encourage fluid intake; concentrated urine is more irritating to the bladder and may cause incontinence.
- Comfortable clothing which is easy to adjust may make coping much easier. Specially adapted garments are available; your District Nurse should be able to advise.
- Consider getting a commode.
- A mattress and/or chair protector may be a good idea to prevent soiling of furnishing.

When to call for help

- If someone suddenly becomes incontinent, is passing urine frequently or the urine has a strong odour, let your doctor know.
- Keep the skin as clean and dry as possible to prevent soreness.

If it has to be endured

If the incontinence cannot be prevented, your GP or District Nurse will be able to supply incontinence pads. The District Nurse will also be able to advise on what specially adapted garments are available. (See our Factsheet 21, ‘Specialist Clothing’).

Incontinence can seem very hard to cope with. Do accept help: it may be difficult to talk about, but your GP and District Nurse will understand and will be able to help you.

Nausea and vomiting

Nausea is the unpleasant sensation of feeling sick. Vomiting is the mechanical action of being sick. While nausea is very common in people who are seriously ill, it is not common in MND

What causes it?

- Medications, e.g. painkillers
- Constipation
- Emotional distress and anxiety

How you can help

- Make sure any anti-sickness medications are taken as prescribed.
- Monitor the severity of the problem.
- Keep the room cool; a fan may help.
- Putting a cool flannel on the forehead; it is often soothing.
- Have a clean receptacle close at hand just in case.
- Encourage the person to take small sips of fluid or to suck ice cubes when feeling nauseous.
- Avoid acidic foods and fluids.
- Ensure regular laxatives if the cause is constipation.

When to call for help

- When you feel you need help.
- Persistent vomiting may mean that drugs need to be given by an alternative route, e.g. suppositories or injections. These need to be organised by a nurse or doctor.

Pain and pain relief

This is difficult to define. Everybody experiences pain differently so pain is what the person experiencing it says it is.

What causes pain?

- Physical causes - these may be related to MND, e.g. poor circulation causing cramps, immobility leading to pain from pressure points or unsupported arms hanging from shoulders.
- Emotional, spiritual or social causes - these non-physical aspects may cause physical pain already present to increase (For example, people who are anxious or depressed may appear to experience greater pain than people who are not.)

What you can do

- Gentle rubbing or massaging of painful limbs, frequent changes of position, supporting arms with cushions or pillows.
- If painkillers are prescribed it is better to keep the pain at bay, so encourage the taking of painkillers regularly, as prescribed, even if there is no pain when they are due.
- Ensure painkillers prescribed to be taken "when needed" are taken for breakthrough pain.
- Use other methods of pain relief such as gentle massage, heat pads, and relaxation techniques.

Assessing and monitoring pain

In order to achieve good pain control, the pain has to be assessed carefully so the right medication can be given. Keep a note of how things are and note any changes in the type or position of the pain. Have your notes ready for visits from doctors or nurses, this information will help them assess the pain and decide what to do to help.

Monitor the pain in terms of:

- Patterns of pain: Where is the pain? How far does it extend?
- What makes it worse? What makes it better?
- Types of pain: Is it an aching, stabbing, burning or shooting pain?
- How many painkillers are being taken: Do they help? How long for?

When to call for help

- Any time that you are worried.
- When there is a new pain or a worsening of an old pain.
- When sleep is disturbed by pain.
- When painkillers do not seem to be working very well or for very long. It may be a stronger dose or different type of painkiller is required.
- When painkillers are causing troubling side effects, e.g. sickness, constipation, drowsiness or confusion

Further help for pain relief

Some pains are not relieved by oral medications. If that is the case, your doctor or nurse may refer onwards for:

- An appointment with a doctor who specialises in pain control.
- Massage or aromatherapy.
- Physiotherapy.
- 'Nerve blocks' in extreme cases.

Morphine and pain control

Many people are frightened by the thought of taking morphine, fearing addiction. Used correctly it is a very valuable painkiller and addiction is not usually a problem.

What is morphine?

Morphine is a strong painkiller. It belongs to a group of drugs called opiates, and works very well on most types of pain. It is also sometimes used in MND to control feelings of breathlessness.

Are there other painkillers?

Yes, other opiates are used for the control of pain. A doctor will prescribe them if he/she thinks they will be effective. If one drug doesn't work, then the doctor will suggest another one.

Syringe drivers

A syringe driver is a lightweight battery operated pump that is used to deliver continuous medication, under the skin over a 12-hour or 24-hour period. It is quite small (about 8 x 3 inches) so will fit into a large pocket, e.g. pyjama breast pocket, and should not hinder most everyday activities. Diamorphine is usually administered by a pump, as it is easily absorbed. It may be combined with other medications for nausea, agitation and other symptoms.

A syringe driver may be used for several reasons. If there is, for example

- Difficulty in swallowing tablets or reduced absorption from the stomach.
- Persistent nausea or vomiting that cannot be controlled with oral medication.
- Extreme weakness or restlessness.
- Poor pain control with oral medication.

A syringe driver is used to achieve a constant level of medication and gain control of symptoms. When a syringe driver is used the medication is delivered continuously. Additional injections can be given if symptoms "breakthrough" and the dosages in the syringe driver will be adjusted accordingly.

How does it work?

A fine needle is inserted under the skin, usually in the upper arm, thigh, stomach or chest. The syringe and driver are attached to a small infusion set (tube/needle) which is held in place with a small clear dressing. The box is connected to the needle by a fine, flexible tube, so the box is, for example, in a breast pocket while the needle is in the thigh.

Once the battery has been inserted, the driver will start and a small light will flash on and off continuously. A faint "whirring" sound will be heard from time to time. This is perfectly normal; it is the motor in the driver moving the syringe to deliver the medication.

Who looks after the syringe driver?

Normally the syringe will need to be changed once a day and a District Nurse will do this, but some people monitor their own syringe drivers. If someone goes away from home, e.g. for a holiday, then it is usually possible for a local District Nurse to deal with it, but that would need to be arranged in advance.

What can you do?

- Look out for the signs of redness or discomfort at the needle site.
- Remember that "top up" injections may be necessary for a day or two after starting until the correct drug regime is found.
- Ensure the driver and needle site are kept dry. (It is possible to have a bath with a syringe driver attached as long as you are careful.)

When to call for help

- If you have any worries, contact one of the nurses or doctors involved.
- If you think the battery has gone flat, e.g. the light stops flashing, the slight whirring noise stops, or the syringe doesn't seem to be emptying at the expected rate.

Anxiety

Anxiety is a mixture of feelings. Such feelings include fear, worry, being "on edge" or being "panicky"

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Why does it happen?

It can be difficult to find out why some people get anxious, but it commonly happens when people are feeling very ill. One problem when we get ill is that there is a lot of uncertainty and this may make people feel especially anxious. Sometimes people try to "bottle it all up" and this can make them feel worse.

What are the symptoms?

There are many symptoms of anxiety

- Tension, worry, fear or dread.
- Difficulty sleeping (especially getting off to sleep at night).
- Restlessness, agitation, irritability.
- Shortness of breath, tingling fingers, feeling the heart racing, frequent need to go to the toilet.

What can be done to help?

When anxiety comes on with depression, anti-depressants may help.

- Sometimes just talking to a friend, a relative or a professional can help. Talking can help someone decide whether they want to talk about their fears or not. Sometimes it really doesn't help to talk either!
- Distraction may help too and keeping busy. (Is there a day centre available which offers crafts, art therapy, or other diversions?)
- Complementary therapies such as aromatherapy or hypnotherapy may help.
- Help with pain and other symptoms often makes a difference.
- Exercises to help control breathing and anxiety can be taught by physiotherapists and occupational therapists.
- Relaxation techniques may also help.

MND Scotland offers a counselling service which might help reduce anxiety, contact us on 0141 332 3903 to find out more.

What about the carer's anxieties?

Carers can also become very anxious. Anyone caring for someone has moments when they feel very anxious. If you begin to feel you just can't cope, or things are getting too much for you, tell your doctor or any of the nursing team visiting the person you are caring for. They will be able to help you too, and they will understand.

Depression

Everyone has bad days when they feel low and people with a serious illness can expect to feel sad sometimes. However, in some people these normal experiences may become more severe and persistent. It is important to recognise this when it happens as something can often be done.

Why does it happen?

For people with serious illnesses there are many things, in addition to the illness itself, which make depression more likely

- Physical symptoms; especially pain.
- Having had depression in the past.
- Family difficulties or worries about other members of the family.
- Loneliness and isolation.
- Some drugs and other treatments, because their side effects may be hard to put up with.

Recognising depression

There are a number of warning signs of depression, although none of these on their own is sufficient to diagnose depression. However, a combination of symptoms may indicate possible depression

- Feeling low or sad for more than several days in a row.
- Unable to enjoy things which used to bring pleasure.
- Feeling you can't go on and want to just 'give up.'
- Loss of appetite.
- Poor sleep, especially early in the morning.
- Poor concentration.
- Feeling tired all the time.
- Being snappy or irritable.

One of the difficulties about diagnosing depression is that many patients with serious physical illnesses lose their appetite or sleep badly anyway and so there may not necessarily be signs of depression.

What you can do

The most important thing is to recognise the problem and to try to get the person to talk about it. Acknowledging that there is a problem and talking about it will enable you to seek the professional help needed. If someone is depressed, a "friendly chat" will not really do much to help.

Remember depression is not a sign of weakness and the sufferer cannot just "Snap out of it."

Helping someone still feel useful

Many sufferers from depression think that just because they cannot do everything they used to do (the shopping, gardening, looking after the children or grandchildren, etc) they are now "useless". Not surprisingly this makes them feel gloomier. It will help if you can find jobs the person can still do within their limitations, so they are being useful, e.g. preparing the vegetables for a meal. Carers should try not to do everything themselves, even if you can do it more quickly. That will simply emphasise the sense of "being a burden" and useless!

If you think you may be suffering from depression yourself, do talk to someone about it. Carers need support as well as the people they are caring for if they are to be able to continue providing care.

MND Scotland offers a counselling service which might help, contact us on 0141 332 3903 to find out more.

Breathlessness

Breathlessness (dyspnoea) is the sensation of not being able to get enough air. People with MND can often lose the ability to take deep breaths because of the damage the disease does to the nerves controlling the breathing muscles without realising it is happening. Once this has happened a little unusual exertion might cause severe breathlessness. In MND, breathlessness usually shows up first when the person is sleeping. The common pattern is extremely restless nights with intermittent awakenings, which the person might not remember, a morning headache on waking, severe drowsiness during the day and possibly confusion or lack of concentration. See our Factsheet 35 'Breathing Matters' for more information.

Breathlessness can be a very frightening feeling and limits even simple activities. Knowing how to help someone who is breathless can give you the confidence to help with this distressing symptom.

Showing someone what they should do when they become breathless will also help reduce their anxiety about attacks and help them cope. The important thing to remember is that people still breathe even when very breathless!

What causes breathlessness?

- MND itself can cause weakened diaphragm and chest muscles making it harder to take in large lungfuls of air.
- Chest infections
- Anxiety or stress
- Chronic lung or heart disease

How can you help?

- Try to stay calm to help give reassurance.
- Find a relaxed, supportive, resting position.
- Encourage slow sighs OUT. This is more helpful and effective than emphasising taking breaths in, and it's easier to do.
- Sometimes distraction can help - try the TV or music.
- Ensure the room is well ventilated, e.g. open a window or use a fan.
- Check that prescribed medication is taken regularly.

What to watch out for

Observe for signs of infection, e.g. high temperature or coughing up green phlegm.

When to call for help

- If there are signs of infection the GP needs to know as antibiotics may be required.
- If the symptom of breathlessness persists, and you are concerned, then seek help.

Oxygen

Sometimes your doctor may prescribe oxygen, although this is less common these days. This comes in small cylinders and so it is easily transportable making it possible to still go out and about. Oxygen is a particularly dangerous gas, especially in enclosed places as high concentrations of oxygen encourage the combustion of materials that do not normally burn with a flame. For example, a lit cigarette that would glow in a normal atmosphere would burst into flames in an atmosphere with only slightly more oxygen than normal.

Non-invasive positive pressure ventilation

It is more probable that breathlessness will be addressed by the provision of non-invasive positive pressure ventilation (NIPPV). Initially this ventilator is used overnight, while sleeping, to reduce the symptoms that are experienced following a disturbed night due to breathlessness. Some MND patients, eventually, find they need to include the use of NIPPV during some parts of the day too. For more information on this see factsheet 40 "The Use of Ventilation in MND".

Further Information

Factsheet 5A,	Assistive Equipment
Factsheet 5B	Maintaining Mobility,
Factsheet 5C	Getting the Best from Physiotherapy
Factsheet 5D	Aids to Maintain Mobility
Factsheet 15	Palliative Care
Factsheet 21	Specialist Clothing
Factsheet 34	Adapting to Swallowing Problems
Factsheet 35	Breathing Matters
Factsheet 36	Oral Health
Factsheet 40	Ventilation in MND
Factsheet 42	Being a Carer
Factsheet 43	Useful Organisations