

Tips

for living with ALS/MND

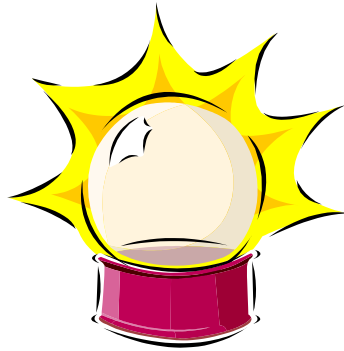


Contents

150+ Tips for Living with ALS/MND

Dressing.....	1
Communicating.....	3
Sitting Transferring and Mobility.....	5
Sleeping or Resting.....	7
Grooming & Toileting.....	8
Eating.....	10
Exercising and Managing Contractures.....	12
Orthotics and Supports.....	13
Household and Pastimes.....	14

Rule Number One



If you don't tell your consultant about a problem, no matter how trivial it seems to you, they can't help you with it. Most symptoms and other problems associated with MND are well known to them and there are usually remedies available.

The information contained in this booklet is not a substitute for professional or medical advice. The needs of individuals should be professionally assessed by the appropriate specialists and their advice taken as to whether a particular intervention is appropriate for the person.

DRESSING



1. Velcro closures can replace standard buttons on clothing, and Velcro tabs can replace buckles or shoelaces on footwear. Some types of trainers and other sports shoe are made with Velcro tabs.
2. Velcro can be purchased as strips at fabric, haberdashery or remnant stores and as adhesive “dots” or “buttons” from stationery suppliers.
3. A long zip-fastener sewn into a side seam of trousers or sports clothing and extended down the leg can permit easier dressing and undressing as well as toileting.
4. Exercise clothing (e.g. track suits, shell suits and similar) with elasticated waist-bands are easier to push down and pull up when dressing, undressing or toileting.
5. A double loop of ribbon or tape (one attached to a belt loop, the other encircling the wrist) makes it easier to lift and lower a pair of trousers when your grip isn't so good, or when only using one hand.
6. A simple pushing or pulling tool to help pull clothing closer to you without stretching can be made from a wire coat hanger straightened out and then bent at either or both ends. Wrap the ends with masking tape to help avoid tearing clothing and to provide a better grip.



7. A circular key ring can be attached to a zipper tab that has a hole in it, allowing fingers or thumb to easily grasp the tab and close the zipper.
8. Depending on what they are attached to, sticky zippers will slide more easily if rubbed with the lead from a lead pencil, wax from a candle or child's crayon or lubricated with some spray-on furniture polish or silicone-based stain preventer.
9. Buttoning can be eased by using elastic loops in place of buttonholes and sewing buttons on with elastic thread. The centre of each button (front and back) can be touched with clear nail polish to seal the threads and make the button stay on longer. This works especially well with buttons on cuffs.
10. Buttons can also be fastened to buttonholes for appearance and Velcro patches placed on the back for closure.

11. A man's pre-knotted necktie can have the loop cut off and be adapted with either a loop of knicker elastic or a plastic or metal clip glued or sewn on the back of the knot to make it easier to fix on a buttoned collar.

12. Canvas shoes can be adapted by sewing a zipper down the side. Any shoe repair shop can modify a pair of shoes in this fashion.

13. Heavy fishing line pulled through zipper tabs and tied in a loop (the knot can be sealed by gently melting it with the heat from a lighted match) makes it easier to pull the zipper closed. This idea works especially well on men's or women's slacks. The loop is invisible and also washes well.

14. A gastrostomy tube can be covered easily with a body size tube-bandage. This will protect clothing from getting soiled by the tube. A 10 to 12 inch wide piece is cut and slipped over the head and arms.

15. Always use shoes that have the same heel height as those worn when leg braces (supports) were fitted. If you don't your feet and ankles may be tilted up or down, which will throw you off balance.



16. A foot that stiffens so much that it's hard to get a shoe on can be more easily slipped into a shoe if the back of the shoe is cut vertically and loosely laced.

17. Elastic shoelaces allow lace-up shoes to be slipped on.

18. Check the soles on sports shoes before purchase. Some brands have soft cushion bubbles on the soles that can make you unsteady, look for firm, flat soles instead.

19. If one side of the body is weaker, it takes less effort to dress this side first. For example, put the weaker arm into the shirt sleeve first, the stronger arm next. Whenever possible, sit while dressing so you can safely rest as needed.

20. If you have difficulty buttoning a shirt or blouse, get a larger size, keep it buttoned all the time and put it on as if it were a pullover shirt.



21. Tube socks (socks without heels that stretch to fit the foot) are easier to put on than those with heels. Socks with a little acrylic fibre in them are also easier to put on for winter wear than socks made of 100 percent wool.

22. Buying clothes one size bigger than normal can help with dressing and undressing.

COMMUNICATING



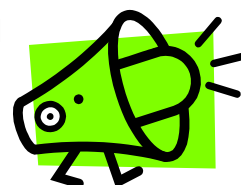
23. When speaking is a problem, writing can sometimes be the obvious solution. Re-usables, such as dry-wipe boards or “Magic Slates,” are often more convenient than a pencil and pad. Small electronic models are also available. Look for memory organisers with simple functions that will write out a word, phrase or sentence on the screen. These instruments are relatively legible, portable and inexpensive.

24. “Chinagraph” pencils can be used to write on most kinds of plastic surface, then be wiped clean with a damp, soapy cloth. Pieces of thick acetate Perspex or plexiglass can be used.



25. The text functions on mobile phones can be used when speaking is difficult. Predictive text can save a lot of time too.

26. The “Speak It! 2” “App” runs on the iPhone, iPod Touch and iPad, costs £1.19 to buy and will speak any text you enter or receive. The App requires iPhone operating system version 3 or later and is available in English, French, German, Italian & Spanish.



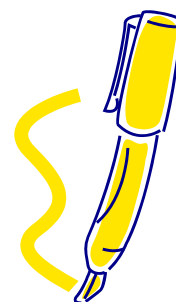
27. For users of Microsoft Office; there is a voice synthesiser built in to the 2003 & 2007 versions of Excel. Open the Excel help menu by pressing F1 and type in the word “Speech” to see how to activate this function in your version. Anything you type into an Excel cell can then be spoken for you. Put Excel with a “Netbook” running XP and you have all the functionality of a Lightwriter for a tenth of the price.

28. Speech recognition is not available in Microsoft Office 2007, for speech recognition functions install a previous version of MS Office if you are running XP, if you are using Windows Vista or later you can run “Windows Speech Recognition”.

29. Large felt tip pens are more easily handled than the average ball-point model.

30. Large diameter ball-point pens are available at office supply stores, pound shops and so on.

31. Pieces cut from an ordinary foam sponge or even some rubber bands wrapped around a pencil/pen can make it easier to grip. Many small pen/pencil grips are available at office warehouse stores.



32. A small rubber ball can be punctured so a pencil can be forced through; this makes an excellent grip for a pencil or other writing implement, pencils or pens can also be pushed through the holes in a practice golf-ball to increase the size to be gripped.
33. A small lazy Susan turntable on the desk top for pens, tape, paper clips, etc., can make them easier to reach.



34. For those who have lost their voice, or are in bed, beepers, buzzers or even a wireless doorbell can be adapted by the addition of a light-touch switch, microswitch or pressure pad to call for someone. The bell push or switch can be mounted on a small board and kept beside the person with MND, or clips added to the back of the board so it can be fixed to a bed or wheelchair. The bell-unit itself can be moved around the house and garden by the carer as they work. This system can also be used when shopping or visiting places of interest to indicate the person would like to "stop here" to see more.

35. Communication around the house between someone who is bedbound and a carer can be helped by using baby alarm type intercoms that plug into the mains. .

36. Telephones which store numbers and allow speed dialling are particularly useful. There are a number of hands-free speaker phones and voice activated models on the market.

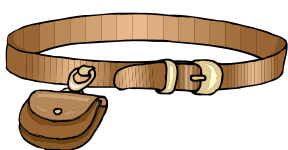


37. Cordless telephones can be useful as they are usually very light and easy to hold and the second handset can be positioned where you are.

SITTING, TRANSFERRING AND MOBILITY



38. An effective transfer board can be fashioned from a length of hardwood, both ends of which should be bevelled, which is sanded, and either waxed and highly polished or varnished with gloss varnish.

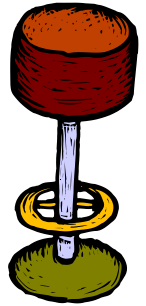


39. Transfers and walking can be assisted by using a wide, securely buckled belt around the waist, which is then grasped to support the person during transfer or steady him/her while walking.

40. A king-size satin pillow case is an excellent aid to use as a draw-sheet for transfer or turning in bed.

41. A bar stool, because of its height, can be a good seat for someone with weak hip and/or knee muscles. Look for one with a wide leg base and with a back and armrests.

42. When rising from a chair with loose arm covers, the covers can be kept from slipping by laying a sheet of art foam (available at art supply stores) or a towelling face-cloth between the cover and the arm rest of the chair.



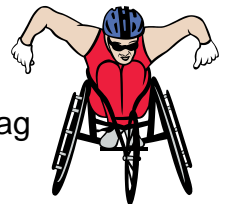
43. Leverage can be increased when moving in bed by using arm elevators constructed with lightweight, wide-based wooded blocks to which dowel handles have been fixed.



44. Fingerless weightlifting or cycling gloves afford a better grip on the rims of manual wheelchairs and also metal handrail when climbing or descending stairs.

45. When travelling, an airline wheelchair can be rented for negotiating narrow doors and passageways.

46. Radio waves can cause unintended motion of power wheelchairs or scooters. Take caution using CB radios or mobile phones when your wheelchair power is on. Also be aware of the location of radio transmitters such as radio or TV stations and two way radios. Try to avoid driving near them.



47. Low cut pile carpeting without padding is safer to walk on than heavy shag or rugs and makes wheelchair mobility at home easier to manage.

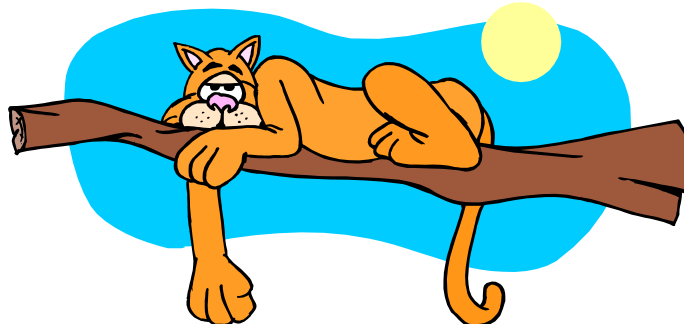
48. Your Occupational Therapist can arrange to install hand rails where you need them most, e.g. around the bath, next to the toilet seat as well as next to steps and stairs.



49. Ramps can be easier to manage than steps or stairs, but more dangerous in wet or icy weather. Cover ramps in coarse-grade roofing felt and/or chicken-wire for extra grip.

50. To easily identify and retrieve a house key from a ring of keys, drill a second hole near the edge of the key so it will hang off centre on the key-ring or use a plastic key end cover, available at your ironmongers or key-cutting shop.

SLEEPING OR RESTING



51. Use satin or nylon sheets and/or pyjamas to make moving and turning in bed easier, but be careful when sitting on the side of the bed as you will slip quite easily when trying to transfer to a wheelchair or commode.

52. A heavy belt or strap tied to the bedposts or a bed frame is a simple way to gain leverage to turn yourself from side to side.

53. For the couple who want a double bed where only one requires a hospital bed, an extra long (80") twin bed can be attached side by side to an electric hospital bed. Order an electric hospital bed that has no headboard (80"), then a king size headboard can be attached to both beds.



54. Washable synthetic sheepskin padding or thermal under blankets can be placed under a fitted sheet for more comfort when lying down. Any of a variety of foam or inflatable camping mattresses serve the same purpose.

55. A U-shaped travel neck pillow can be used to support the neck while lying flat or reclining in bed or in a lounge chair.



56. Fiberfil or down duvets are lighter and warmer than wool or acrylic blankets. It's easier to move underneath or to lift them.

57. Covers tented over a straight back chair at the end of the bed will free your feet and legs while keeping you warm. Using bed corner garters to secure the blanket edges to the mattress is an inexpensive way of keeping them securely tucked. They can be found in the bedding department of discount stores.

58. Long body pillows (bolsters) can be used to prop the back while lying on your side, preventing you from rolling backward. They can also be placed between your knees to decrease pressure and propped to reduce hip contracture.

TOILETING & GROOMING



- 59. Make baths safe by using appropriate aids such as bath-boards or a bath seat to sit on, non-slip bath mat, grab rails, tap rails, tap turners or lever taps.
- 60. An empty half gallon plastic cylindrical container makes a handy floating support for the head and neck to allow shampooing while the bather is reclined in a tub. Avoid overly hot water when bathing, since it causes fatigue.
- 61. For a "dry shampoo," sprinkle cornstarch or baby powder lightly on oily hair and brush it out. Pull a nylon stocking over the brush bristles and brush vigorously to remove more dirt and restore the sheen to your hair.

62. Baby shampoo does not sting if it gets in the eyes.

63. Use a tray for washing hair in bed.

- 64. Cylindrical foam can be purchased in yard lengths and attached or wrapped for extending or enlarging the handle of a razor, comb, toothbrush or other grooming tool. One end of a flat wooden coat hanger can be drilled to accept a tailed comb. This device provides a light and easily handled comb extension.



- 65. Liquid soap containers are convenient to use when attached to the bathroom or shower wall. You don't have to handle a slippery bar of soap or bottle of shampoo or hair conditioner. Soap on a rope does the same thing.

66. Make a slit and pocket in a thick sponge to hold a flat bar of soap. When you wash just squeeze the sponge to get the suds.

- 67. A toothbrush can be adapted for use by weak hands/wrists by cutting the middle rows of bristles down to half their height. With this modification the front and back of the teeth are brushed by the high front and back bristles while the tops are cleaned by the shortened middle bristles. Similar toothbrushes can also be purchased through an appliance catalogue, as can a battery powered model suitable for those lacking the strength or agility to brush their teeth. Look for one with a rotary brush. It's easier to hold in front of your mouth.



68. For better drying, keep the bathroom warm and try dressing in a towelling robe to absorb the moisture after a bath or shower rather than using a towel. You can also use a wall-mounted electric drier to blow air over the whole body.

69. Hand sized loops sewn onto either end of towels can make them easier to manage if your grip is a bit weak.

70. A nail clipper and file combination can be mounted on a sturdy board, eliminating the need for thumb or pinch strength when using these implements.

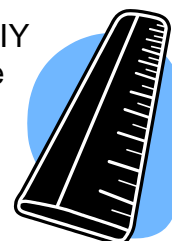


71. Packs of folded toilet tissue in separate leaves are often easier to manage than toilet rolls



72. Use baby wipes instead of toilet tissue. They are easier to hold and you feel (and are) cleaner when you finish using them. If you do use baby wipes don't flush them down the toilet as they don't break up like toilet paper and can block drains; dispose of them in a bin instead.

73. Although specially designed "bottom wipers" are available DIY options are available. A piece of semi flexible plastic (like that used to make small pocket rulers) can be employed to fold toilet tissue for use. The tissue is wrapped around two thirds of the length of the plastic (no sharp edges please), and the remainder used as an extension handle.



74. Another way to provide an extension for cleaning yourself, either with toilet paper or a wash-cloth, is to wrap the one or the other around the working end of a pair of ordinary kitchen tongs.

75. Portable bidets or bidet toilet seats which sit on top of the existing porcelain toilet are available, wash away any residue instead of wiping with paper or cloths.

76. Some people may find urinating into a bottle makes life easier; an old fabric conditioner bottle has a wide mouth and is easy to handle.

77. Leg weakness can make getting off the toilet a problem, raised toilet seats that sit on the existing toilet and raise the seat height are available, grab-rails might also help.

78. Incontinence pads worn at night can decrease the number of times you have to visit the bathroom. They can also be worn on long car trips.

79. If ear wax is a problem don't use cotton buds, get advice from your GP.

80. Muscle weakness can sometimes reduce the rate of blinking causing eyes to feel dry and sore. Use a small pad of cotton wool soaked in clean warm water to clean the eyes outwards from the nose. Make sure the hands are well washed first and use a separate pad for each eye. To relieve soreness your GP can prescribe eye drops.

EATING



81.If you are losing weight or have swallowing problems due to MND a variety of specialist foods, food thickeners, energy drinks and other supplements are available on prescription. Speak to your GP or dietician about the possibility of having these prescribed for you.

82.A moistened paper towel placed under your plate will keep it from slipping on a formica tabletop. In the same way a damp dish towel wrapped around the base of a bowl will keep it from slipping on a smooth work top or tray.



83.Dycem is a non-slip plastic material useful for sitting between plates/bowls and table-tops or work-tops.

84.Search for specialist cutlery and choose lightweight cutlery where possible.

85.The diameter of cutlery and other handles such as toothbrushes can be increased with cylindrical foam (available as pipe insulation at DIY outlets), rubber tubing or a small rubber ball can be punctured so a knife, fork or similar can be forced through. Equally, epoxy resin can be moulded around handles to give the required thickness or shape.

86.Attach cutlery to the hand with homemade straps or Velcro fastenings.

87.Wide-handled plastic mugs are easier to lift when all four fingers can be placed inside the handle. This way a firm grasp isn't needed to hold and tip the cup toward the mouth. Inexpensive insulated mugs with wide handles can sometimes be purchased at sport shops, pound-shops, souvenir shops or supermarkets.

88.Lightweight plastic bowls are easier to handle than glass or ceramic dishes (a rubber mesh mat or damp towel will keep them from slipping).

89.Double-walled bowls and plates that can be filled with boiling water to keep the food warm for slow eaters are available.

90.To avoid pushing food off the plate, try a plate with a deep rim, or a plate guard that clips onto an ordinary plate.

91.Use lightweight plastic cups or mugs, they are often easier to manage than conventional ones. Insulated ones will keep drinks warmer for longer



92. A sports type plastic drink container often has a hole containing a straw in its cover which eases/allows access to its contents.



93. Annoying phlegm can be decreased by limiting the intake of dairy foods, but be sure to get your daily calcium quotient in other ways.

94. Suck crushed ice before eating if you have difficulty swallowing. It helps desensitise the gag reflex.

95. Where swallowing is difficult, a package of frozen peas placed on the front of the neck may prove of assistance by relaxing muscle spasm.



96. When food gathers in the back of the mouth, tip the chin downward, not upward, to improve swallowing.

97. A little meat tenderiser, papaya or pineapple-juice on the back of the tongue will help to break up thick saliva and aid swallowing.

98. A soap holder which has multiple suction supports makes an effective plate, glass or cup stabiliser. This gadget can be purchased in most supermarkets or DIY shops.

99. A simple portable aid to help get the hand to the mouth can be made with any forearm support such as a flat length of wood or even split bamboo (with several slips of velcro tacked on to secure the arm) and attached in the middle on both sides with a pin to two large dowels which are fixed to a heavy wooden base. This forearm prop can be placed on a table where it acts like a seesaw, lifting the hand to the mouth when the elbow is dropped.



100. An extra long plastic straw can be used to eliminate the need to lift a glass when drinking.

EXERCISING AND MANAGING CONTRACTURES



101. Contractures can be measured by folding a piece of paper to match the angle of the joint, tracing the folded edge onto a second sheet and measuring it with a protractor. By keeping a record of the degree of contracture, the caregiver can see progress and is more likely to keep working hard at stretching exercises to correct the contractures.



102. Balancing exercises are important because loss of balance can result in a fall with possible injury. Holding on to someone while standing on each foot alone is a simple way to improve balance.

103. A foot board ($\frac{1}{2}$ to $\frac{3}{4}$ inch plywood padded with a blanket will do) for support at the foot of the bed to keep the feet propped at the ankles during sleep, helps prevent ankle contractures. Of course, this means you must be able to sleep on your back with both feet against the board. You could, however, be on your side with at least one foot against the board for some effect.

104. A board similar to the above; attached to the bed-frame by "G"-clamps, can prevent someone from slipping down the bed while sitting in it.

105. If your heels feel sore while you're lying on your back, place a small pillow under your calves to relieve heel pressure. This same technique can be used during the day to reduce swelling when you prop up your feet.



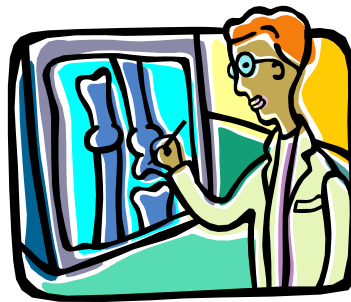
106. Tender heels can be toughened by patting them with a moist teabag at night. When the tea dries, the tannic acid it contains will act to harden (and slightly discolour) the skin. Passive stretching of the knee can be accomplished by placing the calves on a pillow supported by a hassock or kitchen chair. In this way, your heels aren't resting on the supporting surface and there is no heel pressure that might reduce local vascular circulation.

107. The easiest way to stretch heel cord contractures is to stand at arm's length from a wall and place your hands on the wall. Lean toward the wall, bending your elbows, while keeping the heels flat on the floor and the knees straight, and attempt to touch the wall with your chest. If this is too hard you can start with your feet closer to the wall, or bend one knee at a time.

108. Maintain joint flexibility by carrying out range of motion exercises
109. Hand exercises can be fun. Try learning sign language and playing "shadow puppets." Fingers are exercised comfortably by squeezing a washcloth or sponge in a basin of warm water.
110. Poor breathing can sometimes be helped by exercises; simple breathing exercises can be performed by blowing through a straw, blowing up balloons or blowing a ping pong ball on a tabletop or other flat surface. Playing a harmonica, kazoo or other wind instrument is a pleasant way to exercise the lungs.



Orthotics and Supports



111. Ventilation under plastic supports (orthoses) is improved by wearing fish-net panty hose. This can be especially useful in the summer.
112. Leaving leg braces (supports) in the shoes provides an instant shoe horn which may help when slipping the shoes and braces onto your feet.



113. Don't try to trim plastic orthotic supports by yourself. Even using a sharp tool to carve the plastic can cause it to weaken.

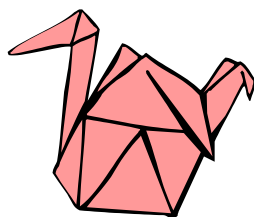


114. Only wear shoes that work well with your orthotics.

115. Take your orthotics with you and try them on in a new pair of shoes before purchase.

116. If you get on particularly well with a specific brand or model of shoe, don't change. It's probably the best shoes suited to your own needs.
117. When you wear orthotics watch out for fifth toe clearance. Many new shoes have straps that can cause painful pressure over this area. Fifth toes vary from person to person in their relative position compared to overall length of the foot.
118. Heel elevation varies from shoe to shoe. As a general rule, people with tight calves do best in the higher shoes.

Household and Pastimes



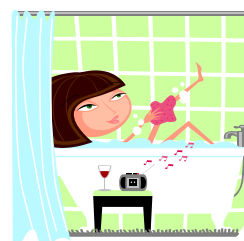
119. An occupational therapist can advise on ways to make daily living activities easier, such as repositioning your kettle closer to your taps, using a wheeled trolley rather than carrying things and so on. Ask your OT for general advice about the layout of your kitchen.

120. When difficulties arise in getting in and out of baths a mechanical hoist can be of help as can a seat that is raised and lowered mechanically.



121. A washcloth mitten is easier for some people to use than a normal facecloth or dishcloth for washing either oneself or the dishes.

122. Easy access to and exit from a bathroom can be provided by removing the door (and even part of the door-frame) and hanging an opaque shower curtain instead. This ends the difficulty of opening and closing the door without sacrificing privacy. Offset hinges can also be used to widen the doorway without removing the door.



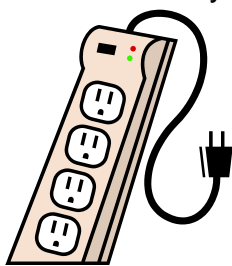
123. Instead of carrying things in your hands or using a wheeled trolley you could also use an apron with big pockets, e.g. a gardening apron, or a bag slung over your shoulder or around your waist.

124. While firm upright armchairs are best for people with MND a motorised “riser-recliner” armchair can help people to stand from a seated position and its variable positions can be more comfortable than an ordinary arm-chair.

125. Wooden blocks can raise the height of existing chairs or beds to make them easier to get into and out of. .

126. Many people might find some of the following to be very helpful in the kitchen:

- Lightweight bowls and utensils
- Jar openers, peelers and graters
- Clamps or Dycem to hold things in place
- Kettle tippers
- Specially designed knobs/handles for cookers taps and so on
- Heat food and cook with a microwave oven positioned at a height suitable for you. Lightweight polythene containers can be used, reducing the risk of accidents.



127. Extension leads can be used to bring electrical power to a

suitable position for you to use.

128. Consider using rocker, dimmer or touch pad switches in place of conventional switches as touch sensitive lamps and dimmer switches only need contact rather than grip to activate them,.

129. People who have difficulties in raising their arms can sometimes improve their functioning by having a raised worktop to support the forearms so they can write or feed themselves. Ways to raise worktop or table heights include:

- .Specialist adjustable cantilevered tables,
- A bed tray with short legs or a wooden box cut to the required height placed on the table
- Forearm supports or mobile arm supports.

130. Sometimes extra leverage is required to operate keys, door handles, taps and the like, your OT can advise and often supply extension levers or keygrips to help.



131. Raised beds or planters supported on blocks can bring the garden up to a wheelchair friendly height.



132. Gardening can be aided by using a length of plastic tubing as a conduit for planting seeds when seated in a wheelchair.

133. Consult on-line versions of newspapers if trying to handle a broadsheet on your own is proving difficult.

134. The dimples on a rubber thimble provide friction to help turn the pages of a book or magazine.



135. Check with your local library for information on how they can supply books to those who are housebound and also ask about what alternative formats they can supply.

136. Where possible get books in electronic/digital form so they can be read from a screen such as a lap-top computer, e-book reader or i-Pad.

137. When hands are too weak to turn the pages of a book but neck strength and control remain, an excellent head centred turner can be fashioned by attaching a pencil-thin wooden dowel, approximately 18 inches long, to the centre of the brim of a tightly fitting cap or sunshade. A soft pencil eraser slipped over the end of the dowel can provide friction for turning the page. An alternative is to have someone place steel paper clips on the corners of the pages and to use a magnet on the end of a stick to pull each page over. Mouth-sticks and commercial pointers are also available if this doesn't work.



138. For fishermen who have difficulty retrieving a line, several devices are available, including a vest with a lightweight harness which holds the fishing rod in an aluminium tube with a locking feature. Also obtainable is an electronic fishing reel (e.g. Daiwa Tanacom) featuring a four-speed control with two manual and two electronic settings.

139. A spring-loaded billiard cue is available for billiards or pool players who lack strength enough to handle the standard cue.

140. If you want to play a stringed instrument (guitar, banjo, ukulele, etc.) but have weak hands and wrists, a soft glove can be modified by gluing individual plastic picks onto the fingers, adding a Velcro strap (for quick sizing) at the wrist and opening the thumb area for easy removal. The glove facilitates plucking and strumming stringed instruments by moving the fingers in a clawing manner, either separately or together.

141. For those who sew, a small magnet glued to the end of a garden cane makes an effective "retriever" for dropped pins and needles.

