

INTRODUCTION

Choosing to die at home is a decision that you and your loved ones make together. Dr. John Turnbull and the ALS Clinic team will discuss the process with you in detail at an appropriate time. They will address your questions or concerns as they arise. If your decision is to remain at home the Clinic will inform your family doctor and your Community Care Access Centre (CCAC) case manager. Please use this brochure as a reference to your consultation with Dr. Turnbull and the clinic.

In most cases an expected death at home is peaceful. The final days and hours can be a very special time for family and caregivers. As with many experiences, preparing in advance and knowing what to expect and what to do will make it easier

REFERENCES

Detailed information on the legal aspects of death is available in *A Guide to Programs and Services for Seniors in Ontario* (2006, p.124) and on the Government of Ontario's website at www.gov.on.ca. (Select "Life Events", then "Personal Loss".)

This brochure was prepared by Marcia Sweet for patients registered with the ALS Clinic of McMaster University Medical Centre, Hamilton, ON. It is based on the experience of former caregivers of ALS patients. © 2008

**McMaster University Medical
Centre: ALS Clinic
1200 Main Street West
Department of Neurology 4U14
Hamilton, Ontario
L8N 3Z5
Phone: 905 521 2100 X 76870
Fax: 905 521 2656**

McMaster University Medical Centre ALS Clinic

DYING AT HOME

**Information for ALS (Amyotrophic
Lateral Sclerosis) Patients, Their
Families and Caregivers**

PLANNING IN ADVANCE

- ask Dr. Turnbull to prepare a Do Not Resuscitate (DNR) form which will allow emergency response teams to alleviate pain, but not to attempt to resuscitate the patient. Give copies to the CCAC and your family doctor
- ensure the patient is assigned “palliative” status (by physician) when appropriate and make this status known to insurance companies and the CCAC (additional hours of home care might be available). If you believe that the hours will not be sufficient contact the ALS Clinic to discuss your options.
- Have will, living will and POA for property and personal care in order.
- make sure that information for all financial and legal matters (will, investments, bank accounts, insurance policies, birth certificates, name of executor, computer passwords) is known to the caregiver and readily accessible
- make a list of all those who need to be contacted at the time of death and consider requesting after hours contact numbers (including the ALS Clinic, family physician, CCAC case manager, funeral home, faith counsellor)
- consider whether or not small children should remain in the home during the last hours; if not, arrange for someone to care for them
- the caregiver should learn how the patients communication or medical devices work if they have not already done so
- make funeral and other (burial, cremation) arrangements
- confirm that your spiritual counsellor (priest, imam, rabbi) will be available for support
- select clothing for the funeral service to be delivered later to the funeral home

- identify nearby friends and family with whom you have a comfort level for the possibility of assistance:
 - to advise the doctor that he or she is needed
 - to contact the funeral home
 - to notify distant family and friends about the death and funeral plans
 - to make a list of telephone numbers and email addresses
 - to answer the telephone and record messages
 - to notify the faith counselor (priest, imam, rabbi) who has agreed to be with you
 - to ask a designated person to care for small children
 - to stay in contact especially during end stages for emotional support



WHAT TO EXPECT IN THE END STAGE (FINAL DAYS)

- long periods of sleep during the day; difficulty waking, or extreme drowsiness
- loss of interest in eating and drinking
- increased restlessness
- shallow or irregular breathing, possibly rapid chest movement
- slowed response to voices or touch
- limbs cool or clammy to the touch
- change in skin colour (blue or grey)

TIPS TO INCREASE COMFORT

- keep the environment as natural, simple and peaceful as possible
- keep interactions to a minimum, respond to questions and concerns, be reassuring.
- learn what is needed through simple questions
- establish in advance the length of visits by family and friends; inform the patient who is in the room
- do not discuss the patient in their presence (what you say may be heard and understood)
- do not be overly concerned about maintaining regular nutrition: offer fluids and light food in small amounts as the patient wishes
- play soft music for its soothing effect
- cuddling or holding each other may comfort both of you

AFTER DEATH HAS OCCURRED

- take time for reflection, prayer, or to say goodbye, then wait where you feel comfortable until the doctor or funeral director arrives
- contact the family doctor who will issue a Medical Certificate of Death (if after hours call the funeral home)
- if you find it necessary to call emergency services (911), be prepared to show them the DNR order immediately upon their arrival
- contact the funeral home
- have someone cover the patient with a sheet
- call the people who have agreed to help you (if you have not already done so)
- notify the ALS Clinic and the CCAC case manager