

## Activities of Daily Living

*"We may wish to struggle along at home."  
– one voice –*

Much of what brings meaning to life is expressed through, and experienced in, activities of daily living (ADL). To assist caregivers in addressing issues related to ADL, a comprehensive assessment tool has been adapted for use with persons living with HIV/AIDS. It is based on the SAFER Tool<sup>1</sup> developed by Community Occupational Therapists and Associates.

In using this tool, three important points must be stressed:

1. understand the context of the living environment of the person, as care and access to resources will vary depending on the person's living situation. Care in a well-equipped apartment can be extremely different from that provided in a hot-plate hotel, boarding house or rooming house
2. whenever possible, consultation with rehabilitation professionals such as physiotherapists and occupational therapists is strongly recommended. Palliative Care includes rehabilitation, especially if it will enhance quality of life
3. include the person in all discussions related to changes in their environment which may be needed to provide safe and effective care

### LIVING SITUATION

#### Access/entrance/security

Many persons living with HIV/AIDS prefer to die at home. To provide optimal quality of life and to enable the person to die at home if he/she chooses:

- develop a plan for caregiver access to the home
- assess the home environment to determine necessary resources and adaptations to maintain a safe, supportive living environment
- make environmental modifications where required to adapt the home setting for providing access and safe care

#### Support network – family/friends

Home support workers and volunteer caregivers may be instrumental in assisting with daily household chores. Assess the person's support network (family, friends, neighbours) and the level of care and support they are able and willing to provide:

- what level of care and support does the individual wish?
- is it realistic given available resources?
- what are the caregiving training needs of family/friends?
- who will provide this training?

#### Stairs

- check that surfaces are non-slip
- ensure adequate lighting on stairways
- encourage the use of handrails when using stairs
- in multi-level housing:
  - consider reorganizing care on one level
  - install a safety gate to prevent falls down the stairs

#### Elevator

- if there is an elevator in the person's building, consider placing a convenient chair so that they can rest while waiting for the elevator
- if necessary, advocate for improved elevator design, i.e. handrails, legible and accessible controls, visual and sound controls

**Environment cluttered**

- negotiate removal of hazardous, unnecessary clutter
- ensure clear walkways
- stabilize unsteady furniture

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**Scatter rugs/flooring**

- remove scatter rugs
- no-wax floors are recommended

**MOBILITY**

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**Positioning**

Teach correct positioning techniques and back care to caregivers. Assess need to alter height of bed or chairs for persons living with HIV/AIDS and caregivers:

- lying:
  - reposition with supports every 2-3 hours
  - use special mattresses, i.e. foam, egg crate, air, to protect skin
- seating:
  - use special seating cushions, chairs with arms to promote safety
- bed care:
  - if required, consider using a hospital bed with working brakes, monkey bar, floor-to-ceiling pole or rope ladder, lifting sheet, bed cradle, mechanical lifting device

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**Transfers**

Teach correct transfer techniques. To facilitate transfer, consider the following equipment:

- bed blocks, chair with arms, cushion, transfer board, vertical pole, lifting sheet or transfer belt, mechanical lift

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**Walking/devices**

The gradual loss of strength and mobility can be demoralizing, and it is important for persons living with HIV/AIDS to maintain activity and strength without overexertion. Focus on ability rather than disability:

- simple, regular exercises can enable the person to maintain strength more effectively than just continuing normal activities
- to assist with walking, recommend well-fitting footwear with enclosed heels and toes
- ensure walking aids are appropriate, height adjusted, correctly fitted and in good working order
- check rubber tips on cane or walker to ensure they are secure
- provide an ice pick for cane in winter
- when leg weakness due to neuropathy, or generalized weakness, impairs ability to walk, a walking aid such as a cane or wheeled walker should be considered

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**Wheelchair/scooter**

- a scooter or electric wheelchair will enable the person to maintain independence when weakness progresses and prohibits walking more than a short distance
- while a scooter may be preferred, as weakness progresses, climbing onto such may become difficult or unsafe
- at that point, electric wheelchairs are recommended, so that the person will not lose a valuable tool for independence

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**Venturing outside**

Maintaining regular activity is crucial to a sense of well-being:

- encourage and/or offer to structure regular outings
  - ensure that appropriate clothing is worn when venturing outdoors
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**Transportation**

Investigate transportation supports in your community, i.e. public transport authority, local AIDS Service Organizations or other volunteer agencies.

- if appropriate, obtain a disabled parking permit and/or arrange for transportation for the disabled
- assist with arranging for transportation to/from appointments

**KITCHEN****Appliances**

Encourage independence where possible:

- place frequently used items at an accessible level
- provide a long reacher for dials at back of stove
- teach fire safety

If confusion is present:

- unplug appliances when not in use
- remove appliances no longer in use
- remove matches and other potential hazards

**Food supply**

Arrange for regular shopping:

- keep the person's personal tastes and needs in mind
- arrange items for easy access
- ensure person can reach items in cupboards and fridge

**FIRE HAZARDS****Smoking**

If the person smokes, recommend:

- a safety ashtray
- supervised smoking, especially in bed
- safety matches
- a fire retardant apron
- adjusting flame height on lighter

If oxygen is in use:

- ensure all are instructed regarding oxygen safety measures, i.e. no smoking while in use

**Smoke detector**

- smoke detectors should be placed appropriately throughout the home
- ensure all are in good working order

**Electric blanket/pad/heater**

If the person uses an electric blanket/pad:

- ensure it is in good working order
- consider pre-warming bed and turn it off when the person is in bed
- do not use if the person is incontinent (wool blankets or duvets are good alternatives)

**Fire exit**

Know location of fire exit:

- ensure accessibility
- review safety route and procedures with all caregivers

**FOOD****Nutrition**

Although people with HIV/AIDS often choose to eat and drink less, the role of adequate nutrition cannot be underestimated. Persistent infections, wasting, or gastrointestinal disorders can contribute to rapid deterioration, weakness and emotional distress.

Consumption of adequate nutritional requirements is important and, when necessary, should be assessed through consultation with a nutritionist.

- dysphagia and problems with malabsorption are common and may require use of special nutritional supplements or alternative feeding techniques
- when eating, consider that correct positioning, a pleasant atmosphere and assistive devices will help maintain appetite and encourage consumption
- appetite, the senses of smell and taste, and food allergies should be taken into consideration when preparing and serving meals
- pay careful attention to food safety when preparing meals
- frequent small snacks/meals throughout the day are generally better than three large meals
- promote independence in eating by using appropriate dishes and cutlery, drinking straw, and a non-slip mat or damp cloth under the place setting
- reduce distractions such as noise
- do not put too much on the plate
- if using cutlery is difficult, suggest finger foods

## HOUSEHOLD

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### Financial

- consult with the person or his/her power of attorney to ensure sufficient financial resources are available to meet the person's needs
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### Bed making

- ensure position of bed gives easy access for caregivers
  - check bed height to ensure proper back care of caregivers
  - assess linen supplies and need for special mattresses and/or other caregiving aids, i.e. extra pillows, foot cradle
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### Cleaning/laundry

- provide appropriate support where necessary
  - maintain body substance precautions with any soiled clothing/linens
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### Child care

Child care is of great concern to those persons living with HIV/AIDS who have children. It is crucial to address the support needs of the entire family:

- provide opportunities for the person living with HIV/AIDS to maintain his/her role as a parent
- assist him/her to delegate tasks where appropriate
- when suitable, and with parental consent, include children in the care team's activities

## DRESSING

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### Dressing/undressing

The person's sense of well-being may be enhanced by maintaining a routine of grooming and dressing:

- choose suitable garments including loose fitting, velcro fastenings, front openings, elastic waistbands, slip-on shoes with non-slip soles, front opening bra or cotton vest
  - dress in sitting position
  - provide devices to assist with dressing, i.e. reacher, long-handled shoe horn
  - lower clothes rod in closet to promote accessibility
  - lay out clothes for the day
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## GROOMING

### Hair care, nail care, shaving, teeth/oral hygiene

Maintaining personal hygiene is often difficult for the dying person due to weakness, depression or social withdrawal. Adequate personal hygiene is important to prevent new infections or exacerbation of previous conditions. Hygiene and grooming may also play an important role in preserving or enhancing the person's self-esteem:

- arrange for haircuts and manicures
- apply make-up to visible KS lesions. This may help reduce isolation by restoring confidence in the person's self-concept and body image
- pay diligent attention to skin and mouth care, especially when physical symptoms are present, i.e. diarrhea, incontinence, dry mouth, mucosal infections, vomiting
- for those who are bed dependent, use hair washing tray with drain
- refer to chiropodist where required

## BATHROOM AND TOILET

### Sponge bath/shower/bath

Select suitable assistive devices and safety equipment and provide assistance as required.

- bath bench, shower extension, grab bar, rubber-backed bath mat

### Contenance (bladder and bowel)

If incontinent:

- consider using a plastic mattress cover, night light, commode, urinal/bedpan, Attends™/Depends™, condom or foley catheter
- reduce fluid intake before sleeping
- establish a regular toilet routine
- provide frequent reminders

### Toilet

Select appropriate equipment:

- ensure privacy if possible
- a raised toilet seat, Versaframe™/grab bar
- ensure toilet roll is within reach
- leave bathroom light on at night
- a sign on the bathroom door may be helpful if the person is confused

## MEDICATION

Persons living with HIV/AIDS may be taking a broad range of medications. It is important to assess the person's:

- knowledge of the medications he/she takes
- ability to read labels
- understanding and follow-through on prescribing instructions
- ability to open containers
- use of non-prescription medications and natural preparations

To assist with medication management, consider:

- a medication dispenser
- instructing family or friends to supervise medications
- medication alarms
- accessing nursing or pharmacy services to pre-pour medications

In some situations, a professional caregiver is required to teach and/or administer medication (i.e. iv therapy, narcotic titration)

### Ordering and storage

As access to a pharmacy and particular drugs like narcotics may be restricted, it is important to anticipate and plan for the person's medication needs:

- store medications safely away from children
- check expiry dates regularly
- if person is self-medicating, ensure easy access
- if confusion is present, a pre-poured or supervised system is recommended
- lock away the remaining medication supply

## COMMUNICATION

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### Use of telephone

- assess locations of telephones and ability to dial
  - consider using a cordless phone, speaker phone, phone with automatic dial
  - place a chair by phone
  - clearly post emergency contacts and phone numbers, and rehearse their use
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### Speech

With advanced HIV disease, speech impairment is not uncommon:

- consider the person's preferred language
  - use a calm, gentle approach and allow time to respond
  - use short sentences, eye contact and touch
  - consider a word/letter board, picture cards
  - consider referral to speech pathologist, if appropriate
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### Vision (reading and writing)

Impaired vision may be experienced by persons with advanced HIV disease. It is frightening and, if it occurs, it substantially increases dependence on caregivers:

- referral to the CNIB can provide invaluable assistance to the person dealing with visual impairment
  - reading: provide good lighting, a tilt table to hold book, large print books, talking books and clocks, volunteer readers
  - writing: use a tape recorder for correspondence
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### Hearing

- consider use of interpreter
  - access to appropriate equipment and communication devices
  - access "peer counselling" where available
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## SOCIAL/LEISURE

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### Social interaction/hobbies/leisure

- encourage social interaction compatible with the person's level of function, interests and wishes. Balance this with the need for social interaction and the opportunity for privacy and social withdrawal
- some persons living with HIV/AIDS may choose to be more dependent, in order to gain/maintain physical and/or emotional contact with others. In such cases, encourage social interaction with partners, family members, friends and volunteers
- it is also important to consider the meaning of special family or community events, and holidays
- the role of pets cannot be underestimated. Attention must be given to supporting the person and his/her family with pet care
- social interaction may include stress reducing techniques such as massage, relaxation, art and music therapy
- while social interaction may enable the person to participate in life as fully as possible, careful attention must be paid to the conservation of energy for activities of choice

- investigate past leisure interests. Hobbies and other interests may need to be modified in order to be pursued and enjoyed. Opportunities for play and interaction with peers is particularly important for young children and adolescents

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### Sexuality/intimacy

- the requirement for affection and a sense of belonging form a basic, common human need. However, the degree and manner of affection and physical contact vary from one person to the next. Many of these feelings are grounded in past experience, culture and personal beliefs. Coming to understand these aspects of a person living with HIV/AIDS will guide the caregiver in how they might extend their affection and human touch. When outright affection or touch is not what is wanted by the person living with HIV/AIDS, there may be underlying reasons which he/she may or may not wish to explore. In all cases, the wishes of the person living with HIV/AIDS should be respected
  - the assumption that people who are dying have no interest in sex is unfounded, and is more probably related to discomfort with discussing issues around sexuality. Although persons living with HIV/AIDS may lose their function and interest in sex, per se, their need for affection, physical contact and sensuality may be greater than ever before.
  - when sex is part of the life of the person living with HIV/AIDS, every effort should be made to provide privacy for the person and his/her partner
  - instruction on safer sex is very important, and consultation with a health professional experienced in sexuality issues may be helpful, should problems arise
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### SUMMARY

This section has discussed many, but certainly not all, of the issues related to ADL and HIV/AIDS Palliative Care. Readers are cautioned to use an individualized approach when assessing the ADL needs of persons living with HIV/AIDS. Experience has taught us that we must always be prepared for new and challenging situations. In doing so, we will support the person living with HIV/AIDS and his/her caregivers, and help them realize a quality of life that promotes autonomy, dignity, comfort, and love.

### REFERENCES

1. Community Occupational Therapists and Associates. The SAFER tool. Toronto, ON: COTA, 1991