

HOW CAN I HELP AND CARE MY LOVED ONES?
THE INFECTED AND AFFECTED

If I can stop one heart from breaking,
I shall not live in vain;
If I can ease one life the aching,
Or cool one pain,
Or help one fainting robin
Unto his nest again,
I shall not live in vain.

By Emily Dickinson (1830–1886)

Could you contribute to this? Yes, just a little act of Compassion of yours can bring so much meaning, comfort and encouragement to help this afflicted one (PWAs) to go a long way in this difficult path that they are traveling in.

When there is love, there is Hope...

The AIDS epidemic knows no age or generation gap. The face AIDS wears is both many and one. The face of AIDS is women and men, children and infants, youth and adults. It is our sons and daughters, brothers and sisters, husbands and wives, mothers and fathers.

Sometimes the face AIDS wears is that of a person without a home or a person in prison. Other times it's the face of a pregnant woman who is fearful she will pass HIV to her unborn child. Sometimes it's a baby or child who has no caregiver and little hope of adoption or being placed in foster care.

Persons living with AIDS (PWAs) come from all walks of life. PWAs represent all racial and ethnic groups, religious backgrounds, and countries of the world. Some are employed; others are underemployed or unemployed. Some are affected by other life-threatening situations such as poverty, domestic or society violence, or intravenous drug use.

Imagine this someone is your loved ones, how will you help them or you won't!

CARING AND SUPPORT FOR SOMEONE WITH AIDS

Some of the Steps to Consider in Caring For Someone with AIDS

- What You Need to Know About HIV & AIDS (refer to the xxxxx)
- Are You in Fear, How can You Cope
- Emotional Support, Where and How Can You Provide
- The Emotional Toll on the PWA
- Other Help You Can Give
- Places to Call for Help
- What To Do During An Emergency
- Giving Care
- How to Get Ready to Take Care of Someone at Home
- Guarding Against Infections
- Protecting Yourself as a caregiver
- Food And Nutrition
- Final Arrangements
- Children With AIDS
- Death and Dying
- How to Help Someone Else Cope With Their Loss Loved ones

Are You in Fear, How can You Cope

If you are feeling fearful and apprehensive about the situation of your HIV status or your loved ones. You can always call us for help at the following few centers:

Kuala Lumpur Aids Support Services Society

KLASS Community Centre Operating Hours:

Tuesday to Saturday: 1.30pm–9.30pm.

KLASS Helpline Operating hours: Wednesday to Saturday: 6.30–9.30pm

Office Tel: 03–4045 6681 , Helpline: 03–4045 3686, Fax: 033–4045 2681

Address : 16–4, Jalan 13/48A, The Boulevard Shop Office, Off Jalan Sentul
51000 Kuala Lumpur, Wilayah Persekutuan, Malaysia.

Website: www.klass.org.my

Malaysian AIDS Council

Treatment Toll Free Line : 1-800-88-1848
24 Hours Info line on HIV/AIDS : 603-7807-7007
Counseling – Direct Line : 603-4043-9711

Address:

No.12 , Jalan 13/48A, The Boulevard Shop Office, Off Jalan Sentul, 51000 Kuala Lumpur, Malaysia.

Website: www.mac.org.my

Emotional Support, Where and How Can You Provide…… a little comfort and peace

If you are caring for a person, it is not just a body; their feelings are important too. Since every person is different, there are no rules about what to do or say, but here are some ideas that may help.

- Keep them involved in their care. Don't do everything for them or make all their decisions. Nobody likes feeling helpless.
- Have them help out around the house if they can. Everybody likes to feel useful. They want to be part of the group, contributing what they can.
- Include them in the household. Make them part of normal talk about books, TV shows, music, what is going on around the world, and so on. Many people will want to feel involved in the things that are happening around them. But you don't always have to talk, just being there is good enough. Just watching TV together or sitting or reading in the same room is often comforting.
- Talk about things. Sometimes they may need to talk about AIDS or talk through their own situation as a way to think out loud. Having AIDS can make a person angry, frustrated, depressed, scared, and lonely, just like any other serious illness. Listening, trying to understand, showing you care, and helping them work through their emotions is a big part of home care. A support group of other people with AIDS can also be a good place for them to talk things out. Contact the KLASS or MAC for information and support that you need. If they want professional counseling, help them get it.
- Invite their friends over to visit. A little socializing can be good for everyone.

- Touch them. Hug them, kiss them, pat them, hold hands to show that you care. Some people may not want physical closeness, but if they do, touch is a powerful way of saying, you care.
- Get out together. If they are able, go to social events, shopping, riding around, walking around the block or just into the park, yard, or porch to sit in the sun and breathe in fresh air.

The Emotional Toll on the PWA

The People who develop AIDS are in many ways the least prepared for the shock of a serious and sometimes terminal illness. Most often they are the young and previously healthy members of society, many of whom were meticulous about their bodies. People in their twenties, thirties, and forties don't normally contemplate death or try to come to grips with their mortality. They are not reflecting back on their lives and what they have accomplished but are looking ahead to what they hope to achieve.

What to look for – when someone who is experiencing anxiety

- Nervous, restless, jittery behavior
- Insomnia
- Change in appetite
- Episodes (sometimes called “anxiety attacks”) during which the person is short of breath, sweating, dizzy; feels faint; or has the sensation that her heart is pounding or skipping beats. The person may tremble or complain of tightness in her chest or a sense that her throat is closing. She may experience diarrhea or have the need to urinate frequently.
- Ambivalence; inability to make decisions
- Becoming easily angered and short-tempered
- Complaint of feeling out of control
- Sense of dread or of impending doom

What to Do

- Remain with anyone suspected of having an episode of acute anxiety
- Offer reassurance calmly and confidently
- Encourage her to discuss her thoughts and feelings. Try to communicate your thoughts and feelings even if the PWA seems confused and irrational or is not able to listen or concentrate.
- Remember that anxiety is a universal feeling, but not everyone expresses it in exactly the same way or handles it in exactly the same way.
- Encourage the anxious person, when calm, to keep a journal – to write out her thoughts and feelings in an effort to pinpoint the exact cause of the anxiety and perhaps to develop some solutions and coping mechanisms.

- Administer anti-anxiety medications if prescribed by the doctor and log their effectiveness.
- Encourage the PWA to learn and practice relaxation techniques, such as meditation, biofeedback, self-hypnosis, or listening to tapes.
- Urge the PWA to seek therapy with a trained professional – a psychiatrist, psychologist, social worker, or nurse therapist
- Explore various support groups for PWAs or caregivers
- Try distractions. Being preoccupied with hobbies, watching television, or reading often aid in relaxation and getting through anxious moments. Music is also known to be a relaxation therapy

What not to Do

- Do not panic in the presence of someone having an anxious episode. It will only worsen the situation. Anxiety attacks are usually short-lived, and the sufferer is usually not in any danger.
- Do not medicate the PWA without consulting a doctor first.
- Do not provide the PWA with recreational drugs or alcohol to calm or soothe her. This will only worsen the anxiety. These substances also pose special risks to PWAs due to the effects it may have on their immune system and this could cause potential interactions with prescribed medications.

When to Consult Your Doctor

- If someone with a history of cardiac or respiratory illness is experiencing anxiety attack symptoms, these symptoms may be of a physical, not psychological, nature. In this situation, take no chances. CALL AN AMBULANCE.
- Inform the doctor of any anxiety the PWA may be experiencing; or discuss the issue during the next office visit. You will need to describe the nature of the anxiety attacks in details, including how often it occurs, how long it lasts, what provokes it, and so on.

What to look for – when someone is coping with depression

- Changes in sleep patterns – either insomnia or increased sleeping hours
- Changes in appetite – lacking the desire to eat or the other extreme of compulsive overeating or bingeing
- Overindulgence in alcohol or recreational drugs as a means of escape or a daily routine
- Self-demeaning comments of one's own behaviors
- Social withdrawal – even from those closest to the person
- Laziness or decreased energy level and interest in those around the PWA
- Absence of laughter and smiles in a previously happy person

What to Do

- Remain with the depressed person even if she doesn't interact with you. Don't allow the person to be alone, even if she would prefer it. Observe her for any physical, behavioral, or emotional changes that you should bring to the attention of her physician or therapist.
- Encourage the depressed PWA to verbalize her thoughts and feelings to someone she trusts and feels comfortable talking to. If you are the recipient of these thoughts and feelings, try to listen with an open mind. Remain non-judgmental. Offer support, understanding and hope.
- Consider therapy or support group.
- Do not take it lightly if the depressed individual expresses feelings or thoughts of suicide or attempts at committing suicide. Ask the depressed person for details of any plan she may have, however impossible it may seem. It is essential that someone should remain close; if these thoughts are expressed.

How to Recognize High-Risk People and Suicidal Behaviors

Consider that a person may be contemplating suicide if she

- Seems profoundly depressed
- Has experienced a loss of self-esteem
- Is restless, agitated, and anxious
- Expresses feelings of guilt and hopelessness
- Is demonstrating self-denigrating or self-destructive behaviors
- Tells you that she feels isolated, unloved, and incapable of loving others
- Seems to have lost touch with reality and the ability to put things into perspective
- Becomes sloppy about her appearance, her job, or her obligations
- Often express thoughts of "doing away with herself" or begins to give away cherished possessions to others

These individuals are known to be at greater suicide risk:

- Anyone with a history of prior attempts
- Individuals who have family members who have attempted or committed suicide
- Depressed people – including those not clinically diagnosed by a therapist as being depressed
- Abusers of alcohol and/or drugs
- People who live alone
- People who have never been married are at highest risk, followed by those widowed, separated, divorced, married without children, and married with children
- Unemployed individuals

- Ill individuals – especially those experiencing chronic pain, chronic disease, recent surgery, or those who are terminally ill
- Women make more suicide attempts, but men are more successful

Note: remember always ask if a suspected person has a plan for committing suicide. Even if the plan seems far-fetched, or no plan exists, take the person seriously. She is crying out for help.

What Not to Do

- Never ignore suicidal thoughts or actions. Don't assume an attempt won't be made. Remain with the person at risk and protect her from harm. Notify the doctor as soon as possible.
- Never tease a depressed person in an effort to "snap them out of it"

When to Consult Your Doctor

- If the depressed person verbalized suicidal ideas or makes a suicide attempt (however half-hearted or inept). This is a psychiatric emergency. GO TO THE EMERGENCY ROOM.
- To inform the physician of any changes in physical or emotional state. Discuss the possibility of depression.

What to look for – when someone is coping with fear

- Rapid heartbeat and palpitations
- Clinging behavior
- Crying
- Diarrhea
- Rapid speech, stuttering; repeating oneself
- Shortness of breath; hyperventilation
- Feeling of tightness in the throat or chest
- Inability to remain alone
- Dry mouth
- Dilated pupils, darting eyes (lack of eye contact)
- Inability to sit still; rocking back and forth

What To Do

- Remain with the fearful PWA until she is calm and in control
- Encourage the fearful PWA to verbalize her thoughts and feelings in as much detail as possible.
- Seek out information to clarify a situation that may be causing fear because there are unknowns. Deliver information slowly and repeat it as often as necessary until the PWA seems to be retaining it. Avoid overwhelming her with a truckload of information that she can't hear or process.

- Allow the PWA to cry if it helps
- Allow the PWA to be in control as much as possible. Encourage her to make her own decisions. This helps to allay fears.
- Remain supportive, thoughtful, empathetic, and hopeful. She has to believe that her feelings are legitimate and that they can be expressed in a non-judgmental atmosphere.
- Draw upon the assistance of therapists, support groups, relaxation techniques, and anti-anxiety medications to help the PWA come to terms with and cope with her fears.

What Not To Do

- Never administer medications not prescribed for the PWA for this specific problems
- Do not make light of fears even if they seem irrational or childish to you
- Do not treat a fearful PWA like a child. Encourage her to be in control and make her own decisions as much as possible.
- Do not try to calm the PWA with alcohol, over-the-counter medications, or illicit substances

What to look for – when someone is coping with anger

- Clenched teeth and tight jaw
- Hostile facial expression and stance
- Clenched fists
- Raised voice
- Verbalization of displeasure—often in a hostile manner
- Verbal abuse (cursing and swearing)
- Physical violence
- Inappropriate actions, such as noncompliance with or sabotage of one's medical treatments
- Thwarting authority
- Bitter communications with loved ones – even severing communications or relationships with friends, lovers, and family, temporarily
- Turning on caregivers – laying blame for problems and circumstances on them even when completely unrelated
- Sarcasm
- Criticism of others, especially health care professionals

What To Do

- Try to put yourself in the PWA's place. Be understanding, empathetic, gentle, and patient.
- Encourage the angry PWA to verbalize, even yell and scream if she feels it is necessary, unless she is out of control and seems violent.

- Discuss her thoughts and feelings seriously, placing an emphasis on reality and how the angry person may regain control of herself. Help her to put things into perspective.
- Encourage the PWA to carefully think through any decision to end medical therapy when that is the object of her rage. Encourage compliance while allowing the PWA to question her treatment and to express her displeasure and frustration. Suggest she discuss with her doctor the addition of new modes of treatment.
- Ask family, friends, and lovers to try and maintain contact with the PWA despite her angry mood. Help each other to deal with the anger.
- Seek professional help in dealing with hostility and share that information with other involved persons if necessary.
- Encourage the angry PWA to join a support group to seek psychotherapy.
- Treat the PWA who is angry as an adult, not as a child. This includes holding her responsible and accountable for her words and actions.
- Accept apologies gracefully and encourage the discussions of hurt feelings and important issues

What Not To Do

- Never pressure an angry and confused person into making poorly thought out and quick decisions.
- Never abandon an angry PWA or retaliate for an angry outburst. Don't give her the "cold shoulder" or the silent treatment. Try to discuss the problem honestly and completely after things have calmed down.
- If argument about medical therapy is raised and is described by the PWA as the main factor, then encourage the PWA to discuss this matter with her own doctor and see if there are any other options. But, never assist an angry PWA to be noncompliant or to sabotage her own treatment.
- Never help or encourage a PWA to displace her anger onto others, including health professionals.
- Never remain in a physically dangerous situation or allow yourself to be physically abused.
- Do not inflame a volatile situation by feeding into it; that is, fighting back, calling names, saying the PWA is ungrateful, or threatening to leave. Matters will only worsen.
- Do not medicate the angry person to sedate her unless you have been directed to do so by a doctor
- Do not physically restrain an angry PWA, as it can injure her.
- Do not trivialize the anger or the situation that prompted the anger. Take it seriously and encourage discussion.
- Do not make decisions for the angry person as if she were an unruly child.
- Do not make it difficult or uncomfortable for the PWA to change her mind or to apologize.
- Do not automatically assume that just because the anger is quick or extreme the issue causing the anger is not justified.

When to Consult Your Doctor

- To discuss the PWA's doctor-directed anger; encourage the PWA to do the same. Remind the PWA to try to remain as calm as possible and to try to listen to the doctor's responses. The PWA should feel free to question the doctor. Expect precise answers in most cases, but also be prepared for the doctor to say she doesn't know the answer when this is the honest truth. The PWA has to be prepared when the doctor has no precise answer or solution to offer.
- To ask for healthy ways to express anger and to deal with it, such as: exercise, therapy, or keeping a journal in which one records thoughts and feelings, including anger. And again, don't forget about support groups, therapy, and relaxation techniques.

What to look for – when someone is coping with Guilt

- Avoidance of the subject, person, or place involved
- Inability to look others in the eye
- Tearful behavior
- Occasional angry outbursts, especially if the guilt arises. It is easier to express anger than to admit guilt, therefore guilt is often transformed into anger.
- Verbal admission of guilt
- Verbalizing blame or being blamed
- Pervasive sense of being wrong
- Suicide-related comments or incidents
- Unrealistic expectations for yourself and/or others
- Insomnia
- Changes in appetite
- Nail biting
- Diarrhea trembling

What To Do

- Encourage the PWA to discuss the situation and her feelings and thoughts honestly, openly, and as calmly and completely as she can with those involved. Likewise, encourage other to express and explore their thoughts.
- Try to be nonjudgmental. Give your opinion only if it is asked for.
- Provide reassurance, apologize when called for (even if you're shy or embarrassed), and accept the apologies of others where appropriate. Then let the incidents in question fade into oblivion.
- Avoid placing blame on anyone (including yourself)
- Seek out support groups and therapy, or call upon our religious beliefs to assist in eliminating guilt-ridden feelings and behaviors.

- Observe the guilt-ridden person for suicidal thoughts, comments, or attempts. Always inquire as to whether a person expressing thoughts of suicide has an actual plan. Ascertain details of the plan and report them to the doctor.

What No To Do

- Never tell someone that her view is wrong or worthless. Each person is allowed her opinion, just as she is allowed to disagree with yours.
- Do not lie or exaggerate
- Do not indulge in the “should haves” and shouldn’t haves” or what if’s.”
- Do not judge yourself or others by unrealistic criteria.
- Do not be unforgiving, condescending, or self-righteous. Put the past behind you and go on – life and the energy to live it are a precious commodity.

When To Consult Your doctor

- As with all emotional turmoil, feelings of guilt should be relayed to the doctor.
- To report the PWA’s suicidal thoughts and deeds; they must be addressed as an emergency.

What to look for – when someone is coping with increase dependence on others for care

- Increasing weakness on the part of the PWA, causing decreasing ability to care for herself independently
- Passivity
- Inability to correctly judge what she can and cannot physically accomplish without assistance
- Regressive behavior
- Seeking assistance from others before trying to do for herself
- Ambivalence about needing help

What To Do

- Assess the PWA’s ability to perform tasks without assistance realistically.
- Encourage the PWA to ask for help only when she needs it.
- Assist the PWA only when you are asked to do so. You may also offer help if you anticipate a need.
- Reinforce the PWA’s strengths. Be supportive. Emphasize what she can, not what she cannot. Do.
- Discuss decisions with the PWA and provide information as needed. However, encourage the PWA to make her own decisions.
- Discuss self-deprecating statements with the PWA when they are made. Foster a positive self-image.

- Facilitate adjustments to hospitalizations by asking questions, noting answers, and remembering to compromise. Remember that doctors and nurses are medical professionals, not maids or babysitters.
- Your “tough guys” approach may be surprising to her loved ones Explain and reinforce to the PWA or the significant others that you are not being uncaring when you encourage the ill person to help themselves.

What Not To Do

- Never infantilize the PWA by doing things for her or making decisions for her if she is capable of doing these things for herself.
- Do not label someone as uncooperative or noncompliant. Labels never help anybody. Talk things over openly and honestly.
- Do not assume that being sick makes the PWA in any way incompetent.

When To Consult Your Doctor

- To discuss obtaining a home health aide or help at home, if needed.
- To discuss questions and answers regarding hospital routines if hospitalization becomes necessary. Also discuss with both your doctor and your caregivers (including hospital staff) ways in which you can retain more control.

Other Help You Can Give

Dealing with hospitals or insurance companies, filling out forms, and looking up records can be difficult even if you are well. Many people with AIDS need help with these tasks.

- Getting a ride to the doctor's office, clinic, drug store, or other places can be a problem. Don't wait to be asked, offer to help.
- Keeping a diary of medical events and other information for the person you are taking care of can help them and any other people who are helping. Be sure the person you are caring for knows what you are writing and they help keep the diary if they can.
- Keeping a record of medicine and other care for the doctor or the other people providing care can help a lot. Make sure you know what drugs the person is taking, how often they should take them, and what side effects to watch out for. The doctor, nurse, or pharmacist can tell you what to do.
- People who are sick sometimes forget to take medicine or take too much or too little. Divided pill boxes or a chart showing what medicines to take, when to take them, and how much of each to take can help.
- If the person you are caring for has to go into the hospital, you can still help. Take a special picture or other favorite things to the hospital. Tell the hospital staff of any special needs or habits the person has or if you see any problems. Most of all, visit often.

Places to Call for Help

Call the **KLASS** Hotline or **MAC** for answers to questions about HIV infection or AIDS, materials on sex and AIDS, or referrals to local organizations in your community. One of the referrals you should ask for is the telephone number.

KLASS Tel: Tuesday to Saturday: 1.30pm–9.30pm

KLASS Helpline operating hours: Thursday to Sunday: 6.30–9.30pm

KLASS was formed to provide support services to People Living with HIV/AIDS, especially the Chinese-speaking community. The services include emotional support and care to all residents and clients, visits to hospitals and homes and counseling.

The Malaysian AIDS Council can provide materials about HIV and AIDS. MAC can also check computer records for organizations in your area dealing with AIDS or materials about HIV or AIDS from health departments.

The MAC Treatment Service can answer questions about treatments for AIDS and diseases linked to AIDS. The Treatment Toll Free Line: 1–800–88–1848, 24 Hours Info line on HIV/AIDS; 603–7807–7007; Counseling – Direct Line; 603–4043–9711

AIDS Action and Research Group (AARG)

The AIDS Action and Research Group comprise lecturers and personnel of University Sains Malaysia, Pulau Pinang. The activities include AIDS education and awareness campaigns, seminars/workshops, training courses, research and counseling that cater for the people in the northern region of the Peninsular Malaysia. AARG had recently expanded its services to the southern region with the set-up of Johor AIDS Action & Research Group in 2001.

Tel/Fax: 04–656–5984/5

E-mail : aargusm@po.jaring.my

All Women's Action Movement (AWAM)

AWAM's is a women's organization dedicated to creating awareness on issues related to women, advocating and lobbying on the status of women in Malaysia and providing a range of services for women in crisis such as crisis help line, referrals and legal clinics. Through AWAM's public education and awareness raising programmes, women and AIDS issues are integrated.

Tel : 03-7877-4221
Fax : 03-7874-3312

Association of Malaysian Medical Assistants

The association of Malaysian Medical Assistants is a voluntary professional body established in 1986. Their aim is to increase the professional knowledge of medical assistants by up-dating members on medical development. This group conducts HIV/AIDS "train the trainers" programme to spread HIV/AIDS knowledge and awareness among its members. Their programme also targets specifically factory workers and women groups in Barisan Nasional.

Tel : 03-2690-5407/8
Fax : 03-2691-1186

Bar Council

The Bar Council works on HIV/AIDS issues through its involvement with the Law, Ethnicity and Human Rights Sub-committee of the Malaysian AIDS council, the Legal Aid Clinics and through individual lawyers committed to HIV/AIDS issues.

Tel : 03-2691-1366
Fax : 03-2692-1345, 2691-4316

Buddhist Missionary Society Malaysia

BMSM holds basic HIV/AIDS awareness campaigns with the aim of strengthening the Buddhist community's understanding of the AIDS pandemic. It also aims to mobilize its branches throughout Malaysia to spread the AIDS prevention messages including sensitizing the Buddhist community on issues relating to the People Living with HIV/AIDS.

Tel : 03-2273-5373
Fax : 03-2274-0245

Community AIDS Service Penang (CASP)

CASP is involved in public education, counseling, and training of volunteers, outreach work with marginalized communities, provisions of emotional or psychological support to People Living with HIV/AIDS and many other activities. Targeted at the northern region states of Peninsular Malaysia, CASP also organized World AIDS Day as a major event every year to publicize their services as well as gather support for the AIDS-cause.

Tel/Fax : 04-2299-566

Federation of Family Planning Associations Malaysia (FFPAM)

FFPAM is a leading NGO in sexual and reproductive health in Malaysia. It advocates and promotes HIV/AIDS awareness and education via RHAM (Reproductive Health of Adolescents Module), a training tool developed for trainers and peer educators, which integrates HIV/AIDS and sexual health. FFPAM was also involved with the development of AIDS/STD Module for Family Life Education. One of their milestones is the setting up of the "Buddies of Ipoh" project by the Perak Family Planning Association. HIV/AIDS information is also provided at its state outlets via the youth clinics and youth advisory centers.

Tel : 03-5633-7514/16/28

Fax : 03-5634-6638

Islamic Medical Association of Malaysia

The Islamic Medical Association Malaysia comprising of Muslim doctors, nurses, paramedics and medical students established a halfway house called "Rumah Soleha" for HIV positive women and children in June 1998. It aims to provide assistance and temporary shelter for HIV positive women who have been abandoned by their families.

Tel/Fax : 03-7729-3173

Malaysian CARE

Malaysian CARE provides care and support services for drug users through its Drug Rehabilitation and Prison Services as well as their Drop-in Centre in Petaling Jaya. Outreach to prisoners, drug rehabilitation centers, streets, homes, hospitals are conducted regularly in which dissemination of information, which covers spiritual and educational (including HIV/AIDS) dimensions, are provided.

Tel : 03-4256-8715

Fax : 03-4251-4044

Malaysian Consultative Council of Buddhism, Christianity, Hinduism, and Sikhism

The Consultative Council, which represents four of the major religious communities in Malaysia, aims to reach out to the general public on prevention of HIV/AIDS via the various religious leaders.

Tel : 03-4041-4669
Fax : 03-4044-7304

Malaysia Dental Association (MDA)

MDA is involved in updating dental practitioners i.e. dentists, dental nurses and the dental surgical assistants by conducting AIDS Update on standardized cross infection procedures and Training on Infection Control Techniques and AIDS and the its impact on the dental industry. Through its branches in the north, south and the east coast of Malaysia, a number of HIV/AIDS seminars/workshops have been held on these topics.

Tel : 03-2095-1532/1495
Fax : 03-2094-4670

Malaysian Indian Youth Club Council (MIYC)

MIYC is committed to youth activities and empowerment of youth programmes for in-school and out-of-schools youth in Malaysia, MIYC has integrated HIV/AIDS educational talks/seminars/workshops to create awareness as well as train its youth leaders to become peer educators.

Tel : 03-4280-1600

Malaysian Medical Association (MMA)

MMA's activities concentrate on education and awareness rising on HIV/AIDS (i.e. talks and forums) amongst medical professionals and the general public. Its main role is to educate and update doctors on recent advances in HIV/AIDS e.g. Epidemiology, clinical diagnosis, treatment, etc.

Tel : 03-4041-8972/1375, 4043-1743
Fax : 03-4041-8187, 4043-4444

Malaysian Mental Health Association (MMHA)

MMHA is involved in education, awareness raising and counseling on mental health. MMHA's involvement in AIDS education s via their annual teenage development and adventure camp which aims to create awareness on sexual health, healthy lifestyle, peer pressure and danger of HIV/AIDS and substance abuse. These camps have proven successful as it is done through workshops and small group discussions and uses young facilitators as role models.

Tel : 03-7782-5499
Fax : 03-77835432

Malaysian Red Crescent Society

Malaysian Red Crescent Society's AIDS education is carried out via its National Blood, HIV/AIDS & Drug Abuse Committee. One of their popular programmes on AIDS is the "Program Remaja Sihat & Sejahtera" which involves the training of youth educators who are then mobilized to train their peers. As this programme covers many states of Malaysia, AIDS education has been imparted numerous schools, clubs and members.

Tel : 03-4257-8177
Fax : 03-4253-3191, 4257-9867

Obstetrics and Gynecology Society of Malaysia

The obstetrics and Gynecology Society of Malaysia was affiliated to the Malaysian AIDS Council to play an important role in the education of mothers and families on HIV/AIDS, particularly in maternity hospitals.

Tel : 03-6201-3009
Fax : 03-6201-7009

Persatuan Pengasih Malaysia (PENGASIH)

PENGASIH (Organization of Reformed Drug Users) runs a drug rehabilitation programme based on the concept of the therapeutic rehabilitation of community. Services include day-care referrals, outreach to clients etc. AIDS education and counseling has been integrated actively in all their programmes in response to the rapid spread of HIV amongst intravenous drug users.

Tel : 03-6201-3179/0287
Fax : 03-6201-3013

Persatuan Perantaraan Pesakit-Pesakit Kelantan (SAHABAT)

SAHABAT was established in 1999 with the goal of providing direct AIDS related services to the people of Kelantan who have been affected or infected by HIV/AIDS. Currently, members of SAHABAT conduct outreach to hospitals, homes, and drug centers and in the process disseminated HIV/AIDS information and referrals to the clients.

Tel : 09-747-2119
Fax : 09-744-6563

Youth with a Mission Malaysia (YWAM)

YWAM conducts street outreach and operates a day-care center called “Kawan” in Pudu, Kuala Lumpur. Most of its clients comprise of drug users, including HIV positive drug users.

Tel : 03-8070-0301
Fax : 03-8076-4116

Compassion Community Services, Kuala Lumpur (CCS)

CCS is a Christian-based organization which provides various services including children’s old folk’s and halfway homes. CCS currently provides shelter to a HIV/AIDS affected child and aims to further embark on servicing children infected with HIV/AIDS.

Tel : 03-778-2211/2
Fax : 03-7784-3213

PT Foundation

PT Foundation or better known as Pink Triangle is involved in community-based work on HIV/AIDS and sexuality. Programmes are targeted at six marginalized groups; People Living with HIV/AIDS, drug users, sex workers, transsexuals, gay men and lesbians. Support services (temporary shelter, day care, basic medical care, counseling, information, referrals) are provided in its drop-in center. Pink Triangle was also the first NGO to establish the “Positive Living”, support group that gives care and support to People Living with HIV/AIDS.

Tel : 03-4044-4611
Fax : 03-4044-4622

Sarawak AIDS Concern Society (SACS)

Affiliated to the Council in March 1999, SACS is involved in educating the people of Sarawak on HIV/AIDS via public education campaigns (talks/seminars) and direct outreach services. SACS also aims to develop culturally relevant materials (IEC) for the large and multi-ethnic groups in Sarawak.

Tel : 082-410-193
Fax : 082-414-193

Shekinah Home Service Sdn Bhd

Shekinah Home, a Christian-based home, provides temporary shelter, counseling and general care and support for drug dependents, including those who are HIV-positive.

Tel : 06-335-6345, 335-0243

Tenaganita Sdn Bhd

Tenaganita is a women's organization representing the rights of women and migrant workers' in Malaysia. Outreach and collective actions on intervention programmes are organized with women in high-risk groups. It is particularly active in advocating the rights of migrant workers in the plantation and industrial sector by handling cases and providing legal counseling and support as well as research and intervention programmes on health and HIV/AIDS.

Tel : 03-2691-3691

Fax : 03-2691-3681

Women & Health Association of Kuala Lumpur

WAKE is a women's organization that provides shelter and care for women and children infected with HIV/AIDS or reproductive health problems and are homeless and abandoned by their families. The service include emotional support and care to all residents and clients, visits to hospitals and homes and counseling.

Tel : 03-2692-6861

Fax : 03-2692-6877

Intan Drop-in Society, Teluk Intan

The Intan Drop-in society is a new member that aims to set up and provide shelter for clients living with HIV and abandoned by families in the state of Perak. Provision of direct AIDS services will be carried out via networks already established with the Teluk Intan Hospital.

Tel : 03-621-9032

Fax : 03-621-6162

What To Do In An Emergency

- Talk to your doctor and health care team about who should be called for what type of emergency.
- Keep a list of their names and telephone numbers by the telephone and in your pocket.
- What may feel like an emergency may only need some telephone help from your doctor, nurse, social worker or home care case manager.
- As with all good planning, you should think about what you will do in different situations **before** they happen.

- We should also know what to do if someone gets seriously ill at home. The more we think about these situations in advance, the more we will act naturally and with relative calm if the situation ever happens.

Giving Care

- People living with AIDS should take care of themselves as much as they can for as long as they can. They need to be and feel as independent as possible.
- They need to control their own schedules, make their own decisions, and do what they want to do as much as they are able. They should develop their own exercise program and eating plan.
- In addition to regular visits to the doctor, many people with AIDS work at staying healthy by eating properly, sleeping regularly, doing physical exercises, praying or meditating, or other things.
- If the person you are caring for finds something that helps them, encourage them to keep it up. An exercise program can help maintain weight and muscle tone and can make a person feel better if it is tailored to what the person can do.
- Well-balanced, good-tasting meals help people feel good, give them energy, and help their body fight illness. People with HIV infection are better off if they don't drink alcoholic drinks, smoke, or use illegal drugs. Keeping up-to-date on new treatments and understanding what to expect from treatments the person is taking are also important.

There are some simple things you can do to help someone with AIDS feel comfortable at home.

- Respect their independence and privacy.
- Give them control as much as possible. Ask to enter their room, ask permission to sit with them, etc. Saying "Can I help you with that?" lets them keep control.
- Ask them what you can do to make them comfortable. Many people feel shy about asking for help, especially help with things like using the toilet, bathing, shaving, eating, and dressing.
- Keep the home clean and looking bright and cheerful.
- Let the person with AIDS stay in a room that is near a bathroom.
- Leave tissues, towels, a trash basket, extra blankets and other things the person might need close by so these things can be reached from the bed or chair.

If the person you are caring for has to spend most of their time in bed, be sure to help them change position often. If possible, a person with AIDS should get out of bed as often as they can.

- A nurse can show you how to help someone move from a bed to a chair without hurting yourself or them. This helps prevent stiff joints, bedsores, and some kinds of pneumonia.
- They may also need your help to turn over or to adjust the pillows or blankets. A medical "trapeze" over the bed can help the persons shift position by themselves if they are strong enough.
- If they are so weak they can't turn over, have a nurse show you how to use a sheet to help roll the person in bed from side to side. Usually a person in bed needs to change position at least every 4 hours.

Bedsore:

Bedsore or other broken skin can be serious problems for someone with AIDS. In addition to changing position in bed often, to help keep skin healthy, put extra-soft material (sheepskin, "egg crate" foam, or water mattresses) under the person, keep the sheets dry and free from wrinkles, and massage the back and other parts of the body (like hips, elbows, and ankles) that press down on the bed. Report any red or broken areas on the skin to the doctor or nurse right away.

Exercises:

Even in bed, a person can do simple arm, hand, leg, and foot exercises. These are usually called "range-of-motion" exercises. These exercises help prevent stiff, sore joints and help keep the blood moving. A doctor, nurse, or, physical therapist can show you how to help.

Breathing:

If someone is having trouble breathing, sitting them up may help. Raise the head of a hospital-type bed or use extra pillows or some other soft back support. If they have severe trouble breathing, they need to see a doctor.

Comfort:

A good back rub can help a person relax as well as help their circulation. A nurse, physical therapist, or book on massage can give you some tips on how to give a good back rub. Put books, remote controls, water, tissues, and a bell to call for help within easy reach. If the person can't get up, put a urinal or bedpan within easy reach.

[How to Get Ready to Take Care of Someone at Home](#)

Every situation is different, but here are some tips to get you started.

- **First, read this guide.** Have the person living with HIV or AIDS read it. Have other people living in the same house as the person with AIDS read it. The information in this section is for both people with diagnosed AIDS and people with HIV infection who are sick and need care.
- **Take a home care course, if possible.** Learn the skills you need to take care of someone at home and how to manage special situations. Your local Red

Cross chapter, Visiting Nurses Association, State health department, or HIV/AIDS service organization can help you find a home care course. See the "Places to Call for Help" section for more information.

- **Talk with the person you will be caring for.** Ask them what they need. If you are nervous about caring for them, say so. Ask if it is OK for you to talk to their doctor, nurse, social worker, case manager, other health care professional, or lawyer when you need to. Together you can work out what is best for both of you.
- **Talk with the doctor, nurse, social worker, case manager, and other health care workers who are also providing care.** They may need the patient's permission, sometimes in writing, to talk to you, but you need to talk to these people to find out how you can help. Work with them and the person you are caring for to develop a plan for who does what.
 - Get clear, written information about medicines and other care you'll give. Ask what each drug does and what [side effects](#) to look out for.
 - Ask the doctor or nurse what changes in the person's health or behavior to watch for. For example, a cough, fever, [diarrhea](#), or confusion may mean an infection or problem that needs a new medicine or even putting the person in the hospital.
 - You also need to know whom to call for help or information and when to call them. Make a list of doctors, nurses, and other people you might need to talk to quickly, their phone numbers, and when they are available. Keep this list by the phone.
- **Talk to a lawyer or AIDS support organization.** For some medical care or life support decisions, you may need to be legally named as the care coordinator. If you are going to help file insurance claims, apply for government aid, pay bills, or handle other business for the person with AIDS, you may also need a power of attorney. There are many sources of help for people with AIDS, and you can help the person with AIDS get what they are entitled to.
- **Think about joining a support group or talking to a counselor.** Taking care of someone who is sick can be hard emotionally as well as physically. Talking about it with people with the same kind of worries helps sometimes. You can learn how other people cope and realize that you are not alone.
- **Take care of yourself.** You can't take care of someone else if you are sick or upset. Get the rest and exercise you need to keep going. You also need to do some things you enjoy, such as visit your friends and relatives. Many AIDS service organizations can help with "respite care" and send someone to be with the person you're caring for while you get out of the house for awhile.

Guarding Against Infections

People living with AIDS can get very sick from common germs and infections. Hugging, holding hands, giving massages, and many other types of touching are

safe for you, and needed by the person with AIDS. But you have to be careful not to spread germs that can hurt the person you are caring for.

Wash your hands

Washing your hands is the single best way to kill germs. Do it often! Wash your hands after you go to the bathroom and before you fix food. Wash your hands again before and after feeding them, bathing them, helping them go to the bathroom, or giving other care. Wash your hands if you sneeze or cough; touch your nose, mouth, or [genitals](#); handle garbage or animal litter; or clean the house. If you touch anybody's blood, semen, urine, vaginal fluid, or feces, wash your hands immediately. If you are caring for more than one person, wash your hands after helping one person and before helping the next person. Wash your hands with warm, soapy water for at least 15 seconds. Clean under your finger nails and between your fingers. If your hands get dry or sore, put on hand cream or lotion, but keep washing your hands frequently.

Cover your sores

If you have any cuts or sores, especially on your hands, you must take extra care not to infect the person with AIDS or yourself. If you have cold sores, fever blisters, or any other skin infection, don't touch the person or their things. You could pass your infection to them. If you have to give care, cover your sores with bandages, and wash your hands before touching the person. If the rash or sores are on your hands, wear disposable gloves. Do not use gloves more than one time; throw them away and get a new pair. If you have boils, [impetigo](#), or [shingles](#), if at all possible, stays away from the person with AIDS until you are well.

Keep sick people away

If you or anybody else is sick, stay away from the person with AIDS until you're well. A person with AIDS often can't fight off colds, flu, or other common illnesses. If you are sick and nobody else can do what needs to be done for the person with AIDS, wear a well-fitting, surgical-type mask that covers your mouth and nose and wash your hands before coming near the person with AIDS.

Watch out for chickenpox

[Chickenpox](#) can kill a person with AIDS. If the person you are caring for has already had the chickenpox, they probably won't get it again. But, just to be on the safe side:

- Never let anybody with chickenpox in the same room as a person with AIDS, at least not until all the chickenpox sores have completely crusted over.
- Don't let anybody who recently has been near somebody with chickenpox in the same room as a person who has AIDS. After 3 weeks, the person who was exposed to the chickenpox can visit, if they aren't sick. Most adults have had chickenpox, but you have to be very careful about children visiting or living in the house if they have not yet had chickenpox. If you are the person who was near somebody with chickenpox and you have to help the person with AIDS, wear a well-fitting, surgical-type mask, wash your hands before doing what you have to do for the person with AIDS, and stay in the room as short a time as you can. Tell the person with AIDS why you are staying away from them.
- Don't let anybody with shingles (herpes zoster) near a person with AIDS until all the shingles have healed over. The germ that causes shingles can also cause chickenpox. If you have shingles and have to help the person with AIDS, cover all the sores completely and wash your hands carefully before helping the person with AIDS.
- Call the doctor as soon as possible if the person with AIDS does get near somebody with chickenpox or shingles. There is a medicine that can make the chickenpox less dangerous, but it must be given very soon after the person has been around someone with the germ.

Get your shots

Everybody living with or helping take care of a person with AIDS should make sure they took all their "childhood" shots ([immunizations](#)). This is not only to keep you from getting sick, but also to keep you from getting sick and accidentally spreading the illness to the person with AIDS. Just to be sure, ask your doctor if you need any shots or [boosters](#) for [measles](#), [mumps](#), or [rubella](#) since these shots may not have been available when you were a child. Discuss any vaccinations with your doctor and the doctor of the person with AIDS before you get the shot.

Children or adults who live with someone with AIDS and who need to get vaccinated against [polio](#) should get an injection with "inactivated virus" vaccine. The regular oral polio vaccine has weakened polio virus that can spread from the person who got the vaccine to the person with AIDS and give them polio.

Everyone living with a person with AIDS should get a flu shot every year to reduce the chances of spreading the flu to the person with AIDS.

Be careful with pets and gardening

Pets can give love and companionship. Having a pet around can make a person with AIDS feel better and enjoy life more. However, people with HIV or AIDS should not touch pet litter boxes, feces, bird droppings, or water in fish tanks. Many pet animals carry germs that don't make healthy people sick, but can make the person

with AIDS very sick. A person with AIDS can have pets, but must wash their hands with soap and water after handling the pet. Someone who does not have HIV infection must clean the litter boxes, cages, fish tanks, pet beds, and other things. Wear rubber gloves when you clean up after pets and wash your hands before and after cleaning. Empty litter boxes every day, don't just sift. Just like the people living with AIDS, pets need yearly checkups and current vaccinations. If the pet gets sick, take it to the veterinarian right away. Someone with AIDS should not touch a sick animal.

Gardening can also be a problem. Germs live in garden or potting soil. A person with AIDS can garden, but they must wear work gloves while handling dirt and must wash their hands before and after handling dirt. You should do the same.

Personal items

A person with HIV infection should not share razors, toothbrushes, tweezers, nail or cuticle scissors, pierced earrings or other "pierced" jewelry, or any other item that might have their blood on it.

Laundry

Clothes and bed sheets used by someone with AIDS can be washed the same way as other laundry. If you use a washing machine, either hot or cold water can be used, with regular laundry detergent. If clothes or sheets have blood, vomit, semen, vaginal fluids, urine, or feces on them, use disposable gloves and handle the clothes or sheets as little as possible. Put them in plastic bags until you can wash them. You can but you don't need to add bleach to kill HIV; a normal wash cycle will kill the virus. Clothes may also be dry cleaned or hand-washed. If stains from blood, semen, or vaginal fluids are on the clothes, soaking them in cold water before washing will help remove the stains. Fabrics and furniture can be cleaned with soap and water or cleansers you can buy in a store; just follow the directions on the box. Wear gloves while cleaning. See the section on gloves for more information on types of gloves.

Cleaning house

Cleaning kills germs that may be dangerous to the person with AIDS. You may want to clean and dust the house every week. Clean tubs, showers, and sinks often; use household cleaners, and then rinse with fresh water. You may want to mop floors at least once a week. Clean the toilet often; use bleach mixed with water or a commercial toilet bowl cleaner. You may clean urinals and bedpans with bleach after each use. Replace plastic urinals and bedpans every month or so. About 1/4 cup of bleach mixed with 1 gallon of water makes a good disinfectant for floors, showers, tubs, sinks, mops, sponges, etc. (Or 1 tablespoon for bleach in 1 quart of water for small jobs). Make a new batch each time because it stops working after about 24 hours. Be sure to keep the bleach and the bleach and water mix, like other dangerous chemicals, away from children.

Food

Someone with AIDS can eat almost anything they want; in fact, the more the better. A well-balanced diet with plenty of nutrients, fiber, and liquids is healthy for everybody. Fixing food for a person with AIDS takes a little care, although you should follow these same rules for fixing food for anybody.

- Don't use raw (unpasteurized) milk.
- Don't use raw eggs. Be careful: raw eggs may be in homemade mayonnaise, hollandaise sauce, ice cream, fruit drinks (smoothies), or other homemade foods.
- All beef, pork, chicken, fish, and other meats should be cooked well done, with no pink in the middle.
- Don't use raw fish or shellfish (like oysters).
- Wash your hands before handling food and wash them again between handling different foods.
- Wash all utensils (knives, spatulas, mixing spoons, etc.) before reusing them with other foods. If you taste food while cooking, use a clean spoon every time you taste; do not stir with the spoon you taste with.
- Don't let blood from uncooked beef, pork, or chicken or water from shrimp, fish, or other seafood touch other food.
- Use a cutting board to cut things on and wash it with soap and hot water between each food you cut.
- Wash fresh fruits and vegetables thoroughly. Cook or peel organic fruits and vegetables because they may have germs on the skins. Don't use organic lettuce or other organic vegetables that cannot be peeled or cooked.

A person living with AIDS does not need separate dishes, knives, forks, or spoons. Their dishes don't need special cleaning either. Just wash all the dishes together with soap or detergent in hot water.

A person with AIDS can fix food for other people. Just like everybody else who fixes food, people with AIDS should wash their hands first and not lick their fingers or the utensils while they are cooking. However, no one who has diarrhea should fix food.

To keep food from spoiling, serve hot foods hot and cold foods cold. Cover leftover food and store it in the refrigerator as soon as possible.

Protecting Yourself as a caregiver

- A person who has AIDS may sometimes have infections that can make you sick. You can protect yourself, however. Talk to the doctor or nurse to find out what germs can infect you and other people in the house. This is very important if you have HIV infection yourself.
- For example, diarrhea can be caused by several different germs. Wear disposable gloves if you have to clean up after or help a person with diarrhea and wash your hands carefully after you take the gloves off. Do not use disposable gloves more than one time.
- If the person with AIDS has a cough that lasts longer than a week, the doctor should check them for tuberculosis (TB). If they do have TB, then you and everybody else living in the house should be checked for TB infection, even if you aren't coughing. If you are infected with TB germs, you can take medicine that will prevent you from developing TB.
- If the person with AIDS has fever blisters or cold sores (herpes simplex) around the mouth or nose, don't kiss or touch the sores. If you have to touch the sores to help the person, wear gloves and wash your hands carefully as soon as you take the gloves off. This is especially important if you have [eczema](#) (allergic skin) since the *herpes simplex* virus can cause severe skin disease in people with eczema. Throw the used gloves away; never use disposable gloves more than once.
- Many persons with or without AIDS are infected with a virus called *cytomegalovirus* ([CMV](#)), which can be spread in urine or saliva. Wash your hands after touching urine or saliva from a person with AIDS. This is especially important for someone who may be pregnant because a pregnant woman infected with CMV can also infect her unborn child. CMV causes birth defects such as deafness.

Remember, to protect yourself and the person with AIDS from these diseases and others, be sure to wash your hands with soap and water before and after giving care, when handling food, after taking gloves off, and after going to the bathroom.

Gloves

Because the virus that causes AIDS is in the blood of infected persons, blood or other body fluids (such as bloody feces) that have blood in them could infect you. You can protect yourself by following some simple steps. Wear gloves if you have to touch semen, vaginal fluid, cuts or sores on the person with AIDS, or blood or

body fluids that may have blood in them. Wear gloves to give care to the mouth, rectum, or genitals of the person with AIDS. Wear gloves to change diapers or sanitary pads or to empty bedpans or urinals. If you have any cuts, sores, rashes, or breaks in your skin, cover them with a bandage. If the cuts or sores are on your hands, use bandages and gloves. Wear gloves to clean up urine, feces, or vomit to avoid all the germs, HIV and other kinds, which might be there.

There are two types of gloves you can use. Use disposable, hospital-type latex or vinyl gloves to take care of the person with AIDS if there is any blood you might touch. Use these gloves one time, and then throw them away. Do not use latex gloves more than one time even if they are marked "reusable." You can buy hospital-type gloves by the box at most drug stores, along with urinals, bedpans, and many other medical supplies. Many insurance companies and Medicaid will pay for these gloves if the doctor writes a prescription for them. For cleaning blood or bloody fluids from floors, bed, etc., you can use household rubber gloves, which are sold at any drug or grocery store. These gloves can be cleaned and reused. Clean them with hot, soapy water and with a mixture of bleach and water (about 1/4 cup bleach to 1 gallon of water). Be sure not to use gloves that are peeling, cracked, or have holes in them. Don't use the rubber gloves to take care of a person with AIDS; they are too thick and bulky.

To take gloves off, peel them down by turning them inside out. This will keep the wet side on the inside, away from your skin and other people. When you take the gloves off, wash your hands with soap and water right away. If there is a lot of blood, you can wear an apron or smock to keep your clothes from getting bloody. (If the person with AIDS is bleeding a lot or very often, call the doctor or nurse.) Clean up spilled blood as soon as you can. Put on gloves, wipe up the blood with paper towels or rags, put the used paper towels or rags in plastic bags to get rid of later, then wash the area where the blood was with a mix of bleach and water.

Since HIV can be in semen, vaginal fluid, or breast milk just as it can be in blood, you should be as careful with these fluids as you are with blood.

If you get blood, semen, vaginal fluid, breast milk, or other body fluid that might have blood in it in your eyes, nose, or mouth, immediately pour as much water as possible over where you got splashed, then call the doctor, explain what happened, and ask what else you should do.

Needles and Syringes

A person with AIDS may need needles and syringes to take medicine for diseases caused by AIDS or for diabetes, hemophilia, or other illnesses. If you have to handle these needles and syringes, you must **be careful** not to stick yourself. That is one way you could get infected with HIV.

Use a needle and syringe only one time. Do not put caps back on needles. Do not take needles off syringes. Do not break or bend needles. If a needle falls off a syringe, use something like tweezers or pliers to pick it up; do not use your fingers. Touch needles and syringes only by the barrel of the syringe. Hold the sharp end away from yourself.

Put the used needle and syringe in a puncture-proof container. The doctor, nurse, or an AIDS service organization can give you a special container. If you don't have one, use a puncture-proof container with a plastic top, such as a coffee can. Keep a container in any room where needles and syringes are used. Put it well out of the reach of children or visitors, but in a place you can easily and quickly put the needle and syringe after they are used. When the container gets nearly full, seal it and get a new container. Ask the doctor or nurse how to get rid of the container with the used needles and syringes.

If you get stuck with a needle used on the person with AIDS, don't panic. The chances are very good (better than 99%) that you will not be infected. However, you need to act quickly to get medical care. Put the needle in the used needle container, then wash where you stuck yourself as soon as you can, using warm, soapy water. Right after washing, call the doctor or the emergency room of a hospital, no matter what time it is, explain what happened, and ask what else you should do. Your doctor may want you to take medicine (antiretroviral drugs) for post-exposure prophylaxis. If you are going to take that, you should begin taking it as soon as possible, certainly within a few hours of the needle stick.

Wastes

Flush all liquid waste (urine, vomit, etc.) that has blood in it down the toilet. Be careful not to splash anything when you are pouring liquids into the toilet. Toilet paper and tissues with blood, semen, vaginal fluid, or breast milk may also be flushed down the toilet.

Paper towels, sanitary pads and tampons, wound dressings and bandages, diapers, and other items with blood, semen, or vaginal fluid on them cannot be flushed should be put in plastic bags. Put the items in the bag, then close and seal the bag. Ask the doctor, nurse, or local health department about how to get rid of things with blood, urine, vomit, semen, vaginal fluid, or breast milk on them. If you can't have plastic bags handy, wrap the materials in enough newspaper to stop any leaks. Wear gloves when handling anything with blood, semen, vaginal fluids, or breast milk on it.

Sex (link to safer sex)

If you used to or still do have sex with a person with HIV infection, and you didn't use latex [condoms](#) the right way every time you had sex, you could have HIV infection, too. You can talk to your doctor or a counselor about taking an HIV

antibody test. Call [MAC Treatment Toll Free](#) at 1-800-88-1848 or [KLASS helpline service](#) for information about HIV antibody testing and referrals to places in your area that you can get confidential or anonymous HIV testing.

The idea of being tested for HIV may be scary. But, if you are infected, the sooner you find out and start getting medical care, the better off you will be. Talk to your sex partner about what will need to change. It is very important that you protect yourself and your partner from transmitting HIV infection and other sexually transmitted diseases. Talk about types of sex that don't risk HIV infection. If you decide to have sexual intercourse (vaginal, anal, or oral), use condoms. Latex condoms can protect you from HIV infection if they are used the right way every time you have sex. Ask your doctor, counselor, or call KLASS helpline or MAC-24-Hours Info line On HIV/AIDS for more information about safer sex.

[Final Arrangements](#)

A person with AIDS, like every other adult, should have a will. This can be a difficult subject to discuss, but a will may need to be written before there is any question of the mental competence of the person with AIDS. You may want to be sure the person you are caring for has a will and that you know where it is.

Living wills, which specify what medical care the person with AIDS wants or does not want, also have to be written before their mental competence could be questioned. You, as the caregiver, may be the person asked to see that the doctors follow the wishes of the person with AIDS. This can be a very hard experience to deal with, but is another way of showing respect for a dying person. You may want to be sure the person you are caring for knows that they can control their medical care through living wills.

Often, people who know that they will die soon choose to make their own funeral or memorial arrangements. This helps make sure that the funeral will be done the way they want it done. It also makes things easier for those left behind. They no longer have to guess what their friend or loved one would have wanted. You may be asked to help the person with AIDS plan the funeral, make arrangements with the funeral home, and select a cemetery plot or mausoleum. You may be able to help the person with AIDS decide how they wish to be buried or if they want to be cremated.

After the death, there will still be things to do. Programs that have been providing help, such as Supplemental Security Income, will have to be officially informed of the death. Some money already sent or received may have to be returned. The will may name you, a relative, or another person as the one to handle these tasks.

[Where to call and get help for final arrangement](#)

Funeral Parlours

1) Thye Heng Funeral /Casket
504 31/4mile Jalan Cheras
56100 K.L
Office : +603-9846352
Fax :+603-9845741

Charges vary depending on what the family can afford. Usually
Charges RM1,000

2) M.I. Casket
12,Jalan Pahang Barat,
off Jalan Pahang,
53000 K.L.
Office : +603-40219140,40219150,40219160
Fax: :+603-4219160

Charges vary .You need to negotiate

3) P.J. Modern Casket
Eric Lim
H/P 0193368068

4) Dr. Goh Tik Ti,
1 Lot 57 Tmn. Melur, Ampang Jaya,
Ampang 68000
Office : +603-42573194

Note : This person helps to give free coffins for Buddhists only.

Further Information and Assistant

Contact persons to call when you need help or further information.

Michael Chow (Faith Helping Centre)
H/P) 0193151505

Peter Daniel (Malaysian Care)
H/p) 0123730421

Jaffar Daud/Abdullah Ghani (Pengasih Malaysia)
Office : +603-62013179

Alex Arokiam (Welcome Community Centre)
Office : +603-60351463

Carol Wilson (Malaysian Care)
Office : +603-77854578

Inspector Kesihatan DBKL
Office : +603-92845166

Children with AIDS

Infants and children with HIV infection or AIDS need the same things as other children -- lots of love and affection. Small children need to be held, played with, kissed, hugged, fed, and rocked to sleep. As they grow, they need to play, have friends, and go to school, just like other kids. Kids with HIV are still kids, and need to be treated like any other kids in the family.

Kids with AIDS need much of the same care that grown-ups with AIDS need, but there are a few extra things to look out for.

- Watch for any changes in health or the way the child acts. If you notice anything unusual for that child, let the doctor know. For a child with AIDS, little problems can become big problems very quickly. Watch for breathing problems, fever, unusual sleepiness, diarrhea, or changes in how much they eat. Talk to the child's doctor about what else to look for and when to report it.
- Talk to the doctor before the child gets any immunizations (including oral polio vaccine) or booster shots. Some vaccines could make the child sick. No child with HIV or anyone in the household should ever take oral polio vaccine.
- Stuffed and furry toys can hold dirt and might hide germs that can make the child sick. Plastic and washable toys are better. If the child has any stuffed toys, wash them in a washing machine often and have them as clean as possible.
- Keep the child away from litter boxes and sandboxes that a pet or other animal might have been in.
- Ask the child's doctor what to do about pets that might be in the house.
- Try to keep the child from getting infectious diseases, especially chickenpox. If the child with HIV infection gets near somebody with chickenpox, tell the child's doctor right away. Chickenpox can kill a child with AIDS.
- Bandage any cuts or scrapes quickly and completely after washing with soap and warm water. Use gloves if the child is bleeding,

Taking care of a child who is sick is very hard for people who love that child. You will need help and emotional support. You are not alone. There are people who can help you get through this.

Death and Dying

Thoughts of death invade the consciousness of the PWA and all of those who are connected to her long before her illness reaches the terminal stages. This period between the knowledge of impending death and actual death and actual death is often referred to as the 'living-dying phase.' This time is overshadowed by fears of leaving one's loved ones, losing one's possessions, not realizing one's dream or aspirations in life, loneliness, sorrow, loss of self-esteem, loss of self-control, changed body image, pain, suffering, and mental regression. These fears are experienced by the dying person as well as by those persons who are significant in his life.

Stages of Dying

- Denial :
 - a. Denial occurs because reality is seen as threatening. Denial helps us to exclude frightening reality from our awareness. We can selectively shut out bad news, thereby protecting ourselves from anxiety and allowing ourselves to participate in other areas of living. Denial permits a gradual management of a crisis and usually leads to the mobilization of more effective coping mechanisms.
 - b. In this stage a PWA may say, "No, not me!" Doctor shopping is common as the individual seeks out a second, third, even forth opinion in the hope that the diagnosis can be changed. People who know and care about the person also experience denial in much the same way, by saying things like, "It can't be true"; "He looks so healthy"; or "He's too young to die." Often, relationships between the dying person and his friends and family members improve during the denial phase as each tries to reassure the other that nothing is wrong.
- Anger :
 - a. Anger occurs when denial is no longer possible. Often this happens when the dying person begins to display signs of illness. An outpouring of envy, resentment, and grief may be directed against caregivers, doctors, nurses, family members—even the person's surroundings. It's important to realize that all grieving has an element of anger to it, and one should not feel guilty about being angry. Yet significant others try to hold back displays of anger toward the PWA, because no one likes to admit to anger toward a dying person. However, by not expressing honest emotions can adversely affect relationships. Some caregivers and loved ones try to disguise their anger, even from themselves. They may repress it to the point of causing physical illness, such as headaches, abdominal pain or high blood pressure.

- b. Anger mounts for the PWA with the experiences of dehumanizing therapies, repeated hospitalizations, changes in lifestyle, loss of control over bodily functions, and loss of one's independence. Strong sentiments of "Why me?" pervade this period. For caregivers, it is a difficult time, but it is important to remember that angry outbursts are not intended to be personal assaults.

- Bargaining
 - a. Bargaining starts as anger lessens. It is an attempt to postpone pain or death by offering good behavior in exchange for a return health. The bargains are usually made with God and are kept secret from others. Even atheists and those who are not religious are known to bargain. The dying and their loved ones realize that there is only a slim chance that bargaining will accomplish something, but it's worth a try. Soon bargaining ends. Typically, it is followed by a period of loss and depression.

- Loss and Depression
 - a. During this stage, anger, bargaining, and stoic behavior are replaced by a period of deep depression. The PWA is silent or not very verbal, and often introspective and sad.
 - b. This stage is very difficult for others to accept and deal with. It is instinctive for loved ones to try to cheer up the PWA. But all attempts to do so have a hollow ring. These efforts to "put on a happy face" are a means to disguise the anxiety of significant others. In reality, the PWA would be better served if friends and family were to simply sit quietly at his side, hold his hand, and even, if asked, to pray with him. If the PWA chooses to talk, just listen and be there.
 - c. Loved ones also experience the loss and depression stage, but in a milder form. They experience it more deeply after the death occurs.

- Acceptance
 - a. Given enough time, a kind of acceptance of impending death develops. This is a state almost void of feelings. Survival becomes no longer necessary, although hope still exists. There is a sense of closure, especially if the PWA has been able to get her affairs in order. Business such as the drawing up of wills, discussion of funeral arrangements,

and closing relationships to the PWA's satisfaction will bring a sense of peace.

- b. Any unfinished business no longer matters. The PWA is physically weak, sleeps a lot, and is only minimally verbal. Often loved ones need more attention and support now than does the dying person. This is not to be mistaken for a happy stage. It is, however, peaceful for the PWA, and this often brings a sense of calm to those around her.
- c. Some individuals never reach this stage of acceptance. They fight to the end – struggling, usually angry. Those who care for them, should view this, as a good and hopeful sign. However, these PWAs often suddenly give up the fight and they, too, die.

Supporting the PWA during the Dying Process

At the terminal phase, the dying person usually knows that death is near, even if he was never explicitly told. He often comes to the awareness and then seeks verification from those he trusts. It is important to be gently honest, leaving the door open for hope. This removes the PWA's fear of deceit.

What to Do

- Live one day at a time
- Be honest and open regarding issues of death and dying. Try to discuss it freely.
- Talk honestly about the future, what will happen upon the person's death (and afterward, if appropriate)
- Say the things to each other that you rarely say, or haven't said. Equally important, listen –without feeling that you need to discuss or converse.
- Allow yourselves to walk in the other's shoes. Try to understand what the other person is going through, feeling, and thinking. Be supportive of one another. Console one another.
- Encourage the PWA to complete the business of dying, such as drawing up a will, establishing a health care proxy, discussing funeral arrangements, and making peace with others. Encourage her to let her wishes be clearly known to all significant others.
- Allow the PWA to die her own way – at home, in a hospice, or in a hospital accepting death or fighting it.

What Not To Do

- Never lie. Even the most anxious PWA will figure out the truth eventually. Be gentle, maintain hope, but be honest.

- Do not avoid the PWA. You need one another's support – now more than ever. Do not hesitate to visit – just call first and agree to follow the PWA's lead.
- Do not avoid discussions of death, dying or plans such as funeral arrangements. Bring up the subject gently and pursue it only if the PWA indicates she wants to talk about it. Follow his lead. Note his wishes and assure her they will be followed.
- Do not dehumanize the dying person or treat a dying person like an object. Remember the person in the body.

What to Discuss with Your Doctor

To the PWA: Discuss face to face with your doctor all aspects of death and dying, including the use of pain and anti-anxiety medication to ease suffering; the decision to be resuscitated or not; and whether you would like to die at home, in a hospice, or in a hospital.

Hospices

Hospices offer a place where a dying person can stay to receive care, not cure, and not treatment. The emphasis is on allowing the person to live out her life in the most pain-free, comfortable, and loving environment possible outside of the home and under the circumstances. The main difficulty with hospice care is that there are not enough beds available. There are also home hospice programs available to PWAs who are expected to live only 3 –6 months longer and wish to die at home. These programs essentially provide for pain control only.

Preparation for Dying at Home

What To Do

- Discuss the issues involved in dying at home with the PWA, caregiver, loved ones, medical personnel, and social workers.
- Set plans in motion. Follow up on necessary telephone calls. Be sure all equipment is in the home prior to the PWA's return.
- Make the arrangements needed with the funeral home and your physician before taking the PWA home.
- Be sure to obtain information about whom to contact when the time comes if the PWA has no private doctor-paramedics or a physician.
- Keep the necessary telephone numbers at hand to ease the logistical process after death occurs.
- Call the paramedics after the PWA dies only if you are told to do so, as for example if you have no private doctor, no doctor is on call at your clinic, and the police tell you to do so. Be sure that the paramedics know that this death was expected and that the PWA is not to be resuscitated.

- Relish every single moment of your time together – don't waste it! Take photos, videos, tape-record conversations if you and the PWA want to and it is appropriate.
- Encourage significant others to call and come visit – to help out. Be one another's support group before, during, and after the PWA's death.
- Make simple but honest explanations to children who are involved. Include them in plans. They know something is going on. Children will be more afraid of the unknown than of the known. Consult professional help (pediatricians, books, child psychologists) to understand what a child's view of death is at different developmental stages so that they can be helped to understand and cope with the loss in age-appropriate ways.
- Take care of yourself as the caregiver at this time. Maintain your own physical and mental health.
- Look to your spiritual beliefs for solace if you are religious.
- Take time out to let the hospital staff know of the PWA's death. They care.

What Not to Do

- Never rush in your preparation to allow a PWA to come home to die. Time is of the essence, but this must be done right. Planning is the key to a smooth transition from hospital to home.
- Do not close your mind to the possibility of death at home. It is nothing to be afraid of. Once it benefits not only the dying but also loved ones, who can have a more quiet and personal good-bye.
- Do not assume anything. Double-check arrangements. Get things in writing from the funeral home.
- Do not call 999 (or your local emergency number) if someone is expected to die and dies. This service is for emergencies, and an anticipated death is not an emergency.

When to Consult Your Doctor

- To discuss the possibility of allowing the PWA to die at home. If the doctor agrees, enlist his help in planning. Obtain additional assistance from social workers, clergy, and nurses, including referrals for support groups and places to secure needed equipment and services.
- To inform your doctor of the name of the funeral home
- To call the doctor when you believe death has occurred.

How to Know If Death Has Occurred

- Death may be assumed to have occurred if all efforts arouse the person have no effect, if the pupils do not shrink when a flashlight is shined directly in the eyes, and if the person has no detectable pulse and seems not to be breathing. Check for a pulse by placing your fingers on the side of the neck or on the wrist beneath the thumb. Listen and feel for breathing by

positioning your ear above the person's mouth and nose; look for rhythmic rise and fall of the chest wall.

How to Help Someone Else Cope with Their Loss Loved ones

Introduction

In this section, we look at some things we know about grief and dealing with death. We talk about what people can do to help move through the grief process and recover, and where to get help. There are also suggestions for those who want to support grieving people.

Grief is a natural response to loss. Although grief is usually thought of as an emotion that follows a death, it is a process that comes after many kinds of losses. When someone dies, especially following a period of illness, there are many losses to mourn and from which to recover.

Multiple losses deepen grief and drain a person's energies. When someone dies of HIV disease (AIDS), the survivor has probably already experienced many different kinds of losses, often too quickly to fully grieve for them and adjust before another occurs. Health has been lost, perhaps jobs, financial security, energy, good spirits, hope for the future, housing, self-sufficiency, memory and the ability, physical abilities, and many aspects of the relationship – companionship, trust, even love. The way two people relate to each other changes when one becomes more and more dependent, withdrawn, or disinterested. The loneliness and sadness for either or both can be overwhelming.

How to Help Yourself Cope

Here are some things that have proven helpful for those who have survived the loss of a loved one. Perhaps they will help you, too.

- Take time to grieve. There's no way to rush recovering from a loss, nor can you push away your feelings forever.
- Find people to talk to, who can understand, and let them be there for you. Allow yourself to ask others for what you need. Use support groups or professional counseling services.
- Write a letter or make a tape to express unspoken feelings and to say good-bye.
- Be kind to yourself; allow yourself feelings and concern, without being judgmental. Forgive yourself. It's natural to feel "crazy" at times.
- Don't expect too much of yourself too soon.
- Avoid making major decisions and changes in your life. Some consistency, routine, and predictability are helpful when you feel in chaos.
- Get help for practical needs -- paying bills, home repairs etc., or ask someone to assist you in getting help.

- Try to take care of each day, each task, and each problem as it comes -- live day by day -- and feel good about just getting through each day. Set small goals.
- Collect memories of the person who died. Talk to someone about your memories. Commemorate the person on important dates and anniversaries in a special way.
- Grieve for the lost dreams, hopes, and expectations. They are just as real for you as the physical person you lost.
- Take time off from grieving, when you're ready, to do something enjoyable or celebrate someone else's happiness. Continue doing things you enjoy.
- Take care of yourself physically, mentally, and emotionally.
- Get enough sleep, nutrition, support; draw solace and strength from faith, art, music, and the love and support of others. Exercise can help release tension, vent anger and allow feelings to emerge in a constructive way.
- Trust that the pain will decrease and life will be better.
- Explore and participate in religion, faith, and spirituality as a resource for hope and support.

How to Help Someone Else Cope

If you are trying to help someone else cope with a loss, these insights from people who are grieving may be of assistance.

- Acknowledge the death -- express your sadness, your concern, your desire to help. Don't say "I know how you feel" if you don't.
- Offer to do something practical to help -- or just do it.
- Simply be there. Be available.
- Stay in touch after the funeral. Often friends stop calling after the first week.
- Talk about the death and talk about the person who died, and share your memories.
- Encourage the person to express feelings, to cry, and to feel okay about his or her feelings.
- Make contact on important dates, anniversaries, and holidays; let them know you're thinking of them.

Grief Is Difficult

Death is a part of life, as birth is a part of life. Society provides little to support people who are grieving. At best, we get a few days off from work, then its back to "normal." Many of us receive messages that encourage us to hide feelings, to grieve bravely and alone, and to quickly replace the loss. For example, you may be told, "You have to be brave for the children" and, "You're still young - you'll marry again/have another child/get over it quickly." People are often uncomfortable with our grief -- they don't know

what to say and try to avoid the subject or the grieving person. They are afraid of our pain and our feelings.

"I had a friend tell me she didn't call me on the day that would have been my son's birthday because it would have reminded me and made me sad. Reminded me? He was all I was thinking of, and nobody called, and I was so lonely."

"Every time I heard someone say, 'I know just how you feel,' I wanted to choke them! They couldn't know, they couldn't guess a tenth of what I felt. It was a way of avoiding talking about what I really was feeling -- I felt that my feelings and I were being casually dismissed."

Grieving Is Work

Grieving is the process that takes a person from loss to living again. Many people think of grief as pain and sadness, but experiencing these feelings is just one of the tasks of grieving.

These tasks often include:

- accepting that the loss is real and permanent;
- experiencing painful feelings;
- adjusting to a life without the person and other associated losses;
- Forming new relationships and a renewed sense of meaning in life.

Each person's grief is different, and the grieving for each person who dies is unique. There is no "correct" way to grieve, no "right" time to be "over it," no "proper" intensity of feelings or expression of those feelings. But in some way, we almost always get to all of these tasks of grieving while coping with loss and recovering.

Grief Takes Time

Many of us dislike hearing the words "it takes time" because we want relief now. There is no timetable for grief, however, and usually no smooth progression through predictable stages. The experience changes again and again along the way. It is important to be reasonable with yourself and allow time to grieve and adjust. Some people put unrealistic limits on grieving, for example, that you should be "done" in one year. There are no rules. Generally, people progress and then fall back. This is a natural part of the process. Experiencing pain, sadness and other feelings seems essential,

although there are individual differences in how these feelings are experienced.

"I somehow thought that when a year passed, I'd feel so different, that mourning would be complete. It is different now, I've come to accept that she's gone, and the reminders of her around me don't hurt as much ... but some things are harder now than when she died. And I think people expect me to be fine now."

Reactions to Grief

There are many emotions that grieving people experience. Some may be strange, unwelcome, or may make you feel as if you're going crazy.

Emotions can include:

- numbness and lack of feeling;
- shock and disbelief;
- yearning for the person who died -- searching for or expecting the person to return;
- panic, anxiety, tenseness;
- anger and guilt -- even at the person for dying or at yourself for not having done enough.
- sadness, depression, hopelessness, despair;
- helplessness, dependency, vulnerability;
- not caring about yourself;
- irritability;
- sense of relief when the person dies after a period of illness, followed by guilt;
- loss of liveliness and spontaneity;
- isolation.

In addition to these various emotional reactions, people tend to experience changes in their mental and physical conditions.

Common mental changes include:

- sense of unreality;
- confusion;
- difficulty concentrating;
- difficulty making decisions;
- preoccupation with the person who died and obsessively reviewing the dying process;
- thinking about suicide;
- humorlessness;
- sense of being unconnected, of being "in your own world."

The physical effects people can experience include:

- sleep problems;
- loss or change of appetite;
- fatigue, lack of energy;
- restlessness;
- stomach distress;
- heightened sensitivity to pain;
- headaches;
- crying, tearfulness;
- weight gain/loss;
- increase/decrease in sexual desire or energy.

Grieving Affects All Areas of Life

Given all the emotional, mental, and physical reactions that can occur, people often find that nearly every task and relationship is affected by their grief. Accomplishing routine tasks and getting through a regular work day can sometimes be very difficult. Relationships can be strained, especially marriages, by new needs and sensitivities and the different reactions each person experiences. While Western culture has a belief that loss draws people closer, you may find that your reactions and needs are quite different from those of others close to you. You may be unable to meet each other's needs at a time when you both feel so empty. It helps to talk openly about feelings and concerns and recognize that individuals deal with situations in different ways

Special Difficulties of HIV– Disease Deaths

Any death of a loved one is difficult to cope with. Most families who have lost someone to an HIV–related illness, however, face additional losses, some of which may not have been resolved along the way. These can include financial losses jobs, homes, savings, loss of friends or support, loss of time from school or work, loss of hopes and dreams. Much of this probably had to be put on hold. After a death you may be faced with tackling the consequences of these other losses, when you have little energy and few resources. Life often revolves around care of the sick person, and after the person is gone, even everyday life may seem to lose purpose and focus. Loss of roles and routines taken on to support the dying person -- nursing duties, scheduling clinic or hospital visits, etc., can be surprisingly unsettling.

Another difficulty is the effect of HIV infection on a person's thinking and emotions. Uncharacteristic or even mean and painful things may have been said, or the disease may have changed the sick person radically. Private feelings and thoughts about this may cause you pain. It will take time to

recover and put the experience into perspective. The dying person may have withdrawn from other family members, and they may need help, too.

A couple's sexual life may have been halted or changed by a positive HIV antibody test, or by the diagnosis of AIDS. Their plans to have children may have had to be discarded. These losses can be newly painful and intense after a partner's death, and feelings about them can be hard to share and difficult for others to grasp.

The irrational stigma attached to HIV disease and AIDS, along with others' fears and misinformation about how a person can become infected or transmits HIV, only adds to the pain, isolation and worries of families. Some people choose secrecy with neighbors, friends, even relatives, rather than risk rejection or discrimination. This can leave survivors cut off from support. Other families choose to be open about HIV disease. Reactions can vary from understanding and overwhelming support to violent acts. These are difficult decisions and people may be isolated from others when they need them most.

When a person with hemophilia or a sexual partner dies of HIV-related illnesses there are sometimes unresolved feelings of unfairness and betrayal. The fact that the person had to struggle first with hemophilia, then was hit with another disease, may add to feelings of shock and unfairness. That the person was infected through the use of the best available medical treatment is a painful irony.

Finally, there is the added serious problem that a survivor -- a partner, a sibling, a parent, a child, or another relative or friend -- may also be infected with HIV, facing the possibility or actuality of treatment regimens and ill health. Partners maybe in limbo for several months before they are certain that they are free from infection and those who cared for the ill person may have concerns about exposure to the virus.

Any of these difficulties can heighten anxiety many times over and compound the grief experience.

What Lies Ahead

When grieving a recent loss, many people need to feel understanding and support. When someone tells you to have hope and to look forward to an end of grief, you may think your feelings are being discounted. At some point, though, you will be ready to feel hopeful. Moving through the tasks of grieving – struggling to accept the reality of the loss; expressing feelings of loss, sadness and anger – are necessary steps for most people to resolve their loss and enter into a new phase of their lives. Even while grieving, you can look forward to a time when there is less pain and a growing sense of

getting on with life. You can have hope and believe that there is more ahead in life for you than the crushing emptiness and sadness you feel with loss. This is not to say you can ever replace the person who died, end all sadness, or live as if the death never occurred that's not possible. But to feel whole and alive again, to enjoy memories once more, and to embrace life anew: These are real and reachable goals.

"Sometimes I just wanted to be done with the past, move on fast, but I found I wasn't ready. Something would go wrong in a new relationship, and I be thrown into confusion and despair, and deep pain about my loss again. But I stuck with it, letting myself grieve, have feelings and all, and I started to move through it and notice changes. My 'deep grieving' happens just once in awhile now, not every day like before, and I smile more at my memories."

Helping Children Cope with Death

Children's concerns are sometimes similar, sometimes different from those of adults. However, because the adults around them are grieving too, children's needs and concerns may go unaddressed. Some responses that children might have to death include the following:

- Separation anxiety -- will they lose other loved ones? Will someone take care of them?
- Magical thinking -- are they responsible for the illness or death because of something they did or did not do, felt or did not feel?
- Meaning of death -- will the dead person return. (Comparisons of death to sleep can lead to fears about sleeping.)
- Physical problems -- such as bed wetting or nightmares.
- Behavioral problems -- decline in school performance, sullenness, refusal to be left alone.

A child who's loved one has died needs honest, open, reassuring answers, and a chance to pose questions in a secure environment. Parents who are afraid to share their pain or cry with children may need help from others in assisting children to express themselves. It is important to include children in the mourning process.

Their participation in commemorative rituals -- funerals or other memorial ceremonies -- can give them a place to mourn. In addition, it can be a comfort to be with children and learn from their different perspective on the grief process.

Getting Extra Help

Grief can cause a wide variety of feelings, reactions and changes, and all of this is to be expected. Sometimes grief is very complicated or prolonged, and then it's especially important to consider professional help. Anyone who is grieving a loss, though, might consider such help. Counselors, therapists and clergy often have training and experience in grief and loss and can play a critical role in your working through grief. Your local treatment center, crisis hotlines and community mental health centers can help you find such resources. Support groups and local bereavement groups can be important sources of understanding, support and alternatives to isolation.

How do you know if grief is unusually complicated, if extra help is needed? Some of the signs are:

- guilt that can't be shaken, that grows into self-hate;
- unrelenting anger and hostility;
- increased use of alcohol or drugs;
- inability to carry out daily tasks and take on responsibilities for months after the loss;
- self-destructive and suicidal thoughts or actions;
- feeling swamped by loneliness, without relief;
- having fears, or panic attacks;
- loss of self-esteem, feeling worthless;
- inability to feel anything.

Anyone grieving can experience these things for a while, but if they last for weeks and months, outside help is needed. Even without these problems, many people find counseling and support groups very helpful.

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