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PREPARING FOR DISCLOSURE

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"Disclosure" means telling someone that you are HIV+. Who to tell about HIV status and how to tell them can be a very complex and personal decision.

When thinking about disclosure, you should consider the following questions:

* Who do you want to tell and why do you want them to know?
* How much are you ready to share or are they ready to hear? and,
* How will disclosing your HIV status affect you and how will it affect the people around you?

Consider where you want the disclosure to take place. It could be at home, at a friend's house, or in a healthcare setting so that support is readily available. The important thing is that you're comfortable in the setting you choose.

Disclosing your HIV status can be stressful. While you may receive love and support from some of the people you tell, others may not be as accepting. It would help if you could find someone that can support you through this difficult time. Remember that the people you tell will need support too.

You do not need to tell everyone about your status. You should tell people that you may have exposed them to HIV so that they can be tested and have the opportunity to seek medical attention if required. If you have a hard time disclosing to others such as those you share needles with, the Department of Health can inform your contacts without even using your name.

You do not have to tell your employer that you are HIV+. If you do tell, remember that, as long as you are performing your job, your employer cannot legally discriminate against you. People with disabilities, including HIV, are protected from job discrimination under the Americans with Disabilities Act (ADA).

Many women find a sense of purpose and increased self-esteem by telling their story. In cases like this, women choose to "come out" in order to benefit the community and religious groups, schools, and other HIV+ people.

Women may want to tell their children. In this case again, it is important to ask yourself why you want to tell them. Will they be angry if you tell them, or if you don't? Do they already suspect that you're sick? You need to consider telling them just enough that will be appropriate for their age and therefore to comprehend. Remember that children will need support too. Try finding books at Kids Talk AIDS (http://www.kidstalkaids.org/).

Women who are dating find it difficult to know when to disclose. Should it be on the first date or when the relationship starts to get serious? Although there is no right answer for this, the longer a women waits, the harder it may become. Be aware that a woman may be prone to violence when disclosing and consider having a neutral third party available.

Studies show that living with a secret such as HIV can be more emotionally harmful than the rejection that could result from disclosure. Women who have kept a secret for a long time feel a sense of relief after telling. Keep in mind that there are community based organizations and AIDS clinics that can offer resources to guide women through the disclosure process.

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In this issue..

We cannot change anything until we accept it. Condemnation does not liberate, it oppresses.

-C. G. Jung, Psychological Reflections

Sleep Quality in HIV+ Individuals

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For persons with HIV infection, sleep disturbances are the third most frequent reason for seeking medical attention and are experienced by up to 70% in this clinical population (Darko et al, 1992; Norman et al, 1990.) Rubinstein and Selwyn (1998) noted that 73% of patients seen in an outpatient clinic complained of sleep disturbances, yet only 28% had any documentation of insomnia in their medical records. They concluded that insomnia is widespread and under diagnosed in HIV infected individuals (Rubinstein and Selwyn, 1998). Insomnia includes difficulty in going to sleep (sleep latency), and disturbed sleep or frequent waking (sleep efficiency), all of which lead to fatigue, excessive debilitating daytime sleepiness and a significantly diminished quality of life (Nokes and Kendrew, 1996, Adinolfi, 2001). Self-perception of sleep is also considered to be directly related to sleep efficiency.

Sleep-wake cycles are determined by two primary factors: circadian and homeostatic. **Circadian factors** are those related to the endogenous circadian pacemaker. The circadian pacemaker has an inherent cycle that is modulated by environmental "zeitgebers," which are stimuli allowing steady state entrainment of the pacemaker to the external environment thus facilitating alignment of the individual to the environment. The major environmental zeitgeber is the light-dark cycle. Alterations in the light/dark cycle have both acute and chronic effects on the observed melatonin rhythm (Dijk et al 1999). Light-dark cycles are perceived visually and then communicated to the body via the secretion of melatonin. Melatonin, produced by the pineal gland, is released daily in a periodic manner with its onset in the late evening and its peak sometime during the early morning. Its levels diminish shortly before sunrise.

Melatonin acts on the circadian pacemaker to induce a state of sleepiness. Thermoregulatory mechanisms also contribute to the initiation of sleep; heat loss (also promoted by melatonin) is associated with sleep onset. **Homeostatic factors** are related to the duration of prior wakefulness: the longer the duration of wakefulness, the greater the pressure to sleep. This homeostatic force is guided by secretory bursts of cortisol that follow typical circadian patterns, such that its nadir occurs a few hours before bedtime, and it peaks just after waketime. The link between cortisol and melatonin is directly related to both internal and external influences that affect both hormones (Czeisler et al., 1995).

The circadian pacemaker and sleep homeostasis play pivotal roles in the functions of everyday living. Improved sleep has been shown to increase immune function in both cancer patients and HIV infected individuals (Kruger and Madje, 1994). Age-related and disease-related changes in the human circadian pacemaker are hypothesized to contribute to overall diminished sleep quality (Dijk et al., 1999).

The precise mechanisms whereby HIV infection alters sleep are not known. It has been proposed that in HIV infection, there is a loss of normal temperature rhythmicity, which contributes to a reduced stimulation of melatonin secretion . It has also been proposed that HIV infection leads to diminished melatonin production (Cagnacci et al., 1997). Both mechanisms result in insufficient exposure of the sleep center to adequate levels of melatonin, thus contributing to shifts in the circadian rhythm of sleep. Certain outside influences have the ability to phase shift rhythms to a normal pattern, including the exogenous administration of melatonin, (Dawson, and Armstrong, 1996; Arendt, 2000). Therefore, the administration of exogenous melatonin to improve sleep quality appears to be a theoretically attractive intervention.

Melatonin is important in the maintenance of biological rhythms and has been widely accepted as a useful marker of the circadian clock in humans because its secretion is directly controlled by the suprachiasmatic nucleus (SCN) (Voultsios et al., 1997). A circadian pattern of melatonin secretion has been documented in serum, saliva, cerebrospinal fluid, amniotic fluid and numerous tissues (Reiter, 2000). Highest melatonin levels are always associated with the night and melatonin is often referred to as the chemical expression of darkness (Reiter, 2000). The day-night melatonin rhythm normally develops in newborns usually coinciding with the development of a normal sleep-wake cycle. In healthy individuals with mature circadian rhythms, melatonin begins to rise as the sun sets and reaches a peak around 2am and then gradually falls to almost undetectable levels during the day. As one ages, the melatonin level begins to form a normal pattern of expression as the person develops their sleeping habits. Disturbances in the rhythms of melatonin have been attributed to sleep problems in the adult population. The SCN, which is located in the hypothalamus, is the main endogenous pacemaker responsible for the timing of physiologic processes to include the sleep-wake cycle, temperature, hypothalamic-pituitary-gonadal axis and melatonin (Voultsios et al., 1997).

When administered in pharmacological doses, melatonin acts as a powerful "chronobiotic," maintaining synchronicity and preventing desynchrony of circadian rhythms (Armstrong, 1989). It has been demonstrated that patients with insomnia have decreased nocturnal melatonin secretion were successfully treated with exogenous melatonin to improve their sleep disorders. Duffy et al., (1996) found that melatonin acted as a "phase-setter" for sleep-wake cycles. The subjects were given placebo or 5mg of melatonin (daily at 10:00pm for 4 weeks). In all subjects receiving melatonin significant changes were noted in onset of sleep and more daytime alertness. Similar results were obtained by other researchers (Oldani et al., 1994; Deacon et al., 1994; and Cagnacci, 1997). Low dose melatonin has been shown to be effective in treating insomnia. The exogenous compound is well tolerated, and its bioavailability appears

unrestricted. There have been no documented side-effects of melatonin except for occasional daytime sleepiness with increased dosages.

Two funded studies conducted by the author have demonstrated that sleep disturbances are a continual problem in HIV infection and the use of melatonin as an alternative to prescribed pharmacological drugs improves overall sleep quality and improves general state of well-being. More studies are needed to continue to validate the use of exogenous melatonin. One must be careful in the use of over-the-counter melatonin as most of the products are not pure. Most of them contain other ingredients that may mask the amount of melatonin you are actually receiving. As with any drug, discussions with your physician would be important.

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International HIV/AIDS Nursing in Zambia

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On a recent visit to Chikankata Hospital, located in Southern Zambia, I was very impressed with the dedication and knowledge of nurses working in HIV care. Many of the enrolled and Registered Nurses had no formal training in HIV/AIDS yet were caring for many who were infected. It was wonderful to see excitement in the eyes of local nurses who recently learned the government had developed an HIV/AIDS training program that included the care team, including all nurse and doctor levels.

We spoke briefly about treatment of HIV with antiretrovirals (ARVs) and the nurses were astonished to hear how many medicines we had available in the USA to treat the infection. They simply could not believe that health care providers had to strongly remind patients to take their ARVs! One nurse commented that the only medicine available in Zambia was Triammune (D4T, 3TC, Nevirapine) and that only the very wealthy people could afford it. She asked me, "How can an American not take their HIV medicines if they have a full stomach, a place to live, and the ability to find a paying job?" Most of her patients are malnourished and are considered lucky if they had more than one meal to eat in the past 24 hours. The nurse also commented that her patients often walk up to 10 kilometers to reach the clinic, the only one in the area.

During our conversation, the nurse mentioned it is very difficult to work with HIV/AIDS patients because they are very sick and often come in crying, begging for ARVs. Once patients do receive ARVs they often share doses with their family members who do not have access to the drug. Often patients do not have the money to ensure continuous ARV treatment and will split doses to make the ARVs last longer. After explaining that this may lead to a more resistant virus she stated, "We have many people dying because of HIV/AIDS. If we gave them medicine then maybe they could have lived a few years longer to help their family. Hopefully we will have access to more medicines in the future. If it were your mom or dad, what would you do?"

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We as a committee would love to hear from you. Do you have ideas for articles? We would welcome anyone who would like to submit an article. Deadline for our next publication date is December 1, 2004. Let us know if you are interested in writing an article.

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