

Table 22-4: Considerations in Planning Home Care for a Child

1. Parents may lose social support from other parents of hospitalized children when their child is discharged.
2. Parents may experience significant guilt for transmission of the virus to their child.
3. When parents are infected themselves, questions of guardianship, custody, and financial planning are more difficult.
4. Parenting skills may need to be refined. Often, for example, parents experiencing anticipatory grief need help in learning how to discipline their children.
5. There is reduced cost of care at home.
6. Pain is the most common symptom across the spectrum of pediatric HIV disease.
7. There are forms of suffering other than pain in the dying child such as other uncontrolled physical symptoms, guilt for making loved ones sad when they get sicker, and lack of ability to mirror the activities of healthy peers.
8. Care of the dying young is often complex and requires an interdisciplinary approach to care.⁶