**End of Life Planning**

**Department of Developmental Services**

Individual Preferences

|  |  |
| --- | --- |
| **Considerations** | Payment/Arrangement |
| Memorial/Casket/Urn |  |
| Flowers |  |
| Funeral Home |  |
| Church/Synagogue |  |
| Scriptures & Poems to Include |  |
| Music |  |
|  |  |
|  |  |
|  |  |

Name/Relationship of Responsible Parties

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Name** | Relationship | Phone # | Address | **Notified at Time of Death** |
| Family Member |  |  |  |  |
| **Conservator** |  |  |  |  |
| **Health Care Agent** |  |  |  |  |
| **Guardian** |  |  |  |  |

*(optional)*

Personal Preferences

|  |  |  |  |
| --- | --- | --- | --- |
| Names & addresses of people who should be notified at time of death: | | |  |
|  | | | |
|  | | | |
|  | | | |
|  | | | |
| Disposition of personal articles: | |  | |
|  | | | |
|  | | | |
|  | | | |
| Donations to charity: |  | | |
|  | | | |
|  | | | |
|  | | | |

**Choice of Funeral Service (check choices)**

|  |  |
| --- | --- |
| 1. Church or Funeral Home: |  |

2. Casket:  Closed  Open

3. Cremation  yes  no

4. Burial  yes  no

5. Funeral:  Public  Private

6. Memorial:  Yes (deceased present  yes  no)

No

7. Calling Hours: Yes  No

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| 8. Memorial gift beneficiaries choice: | | | |  | | | | |
|  | | | | | | | | |
| 9. Favorite hymns/music: | |  | | | | | | |
|  | | | | | | | | |
| 10. Scriptures, poems or other items to include: | | | | | |  | | |
|  | | | | | | | | |
| 11 Disposition of personal items: (to whom and what items) | | | | | | | |  |
|  | | | | | | | | |
|  | | | | | | | | |
|  | | | | | | | | |
| 12. Articles to be buried with: | | |  | | | | | |
|  | | | | | | | | |
|  | | | | | | | | |
| 13. If no clergy is to be involved, would you like to have someone else say a few words at the | | | | | | | | |
| service |  | | | | | | | |
|  | | | | | | | | |
|  | | | | | | | | |
| Name address and telephone number: | | | | |  | | | |
|  | | | | | | | | |
|  | | | | | | | | |
| 14. What would you like said about you at your service: | | | | | | |  | |
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**Burial Arrangements and Information**

**Guidelines**

* The following may be used as a tool for individuals and their families, teams, etc. who may choose or want to prepare for burial/funeral service arrangements prior to death. This is a guideline to help individuals/families complete the process. Other items may be added as needed.

**Death Certificate Information**

Name:       Date of birth:

Social security #:

Father’s full name:       Mother’s full name:

Mother’s maiden name:

Education level:       Interment preference: Burial/Cremation

Religious affiliation:

Type of work *(may include # of years employed)*

Have any funeral arrangements been made?  Yes (see below)  No (go to next question)

Do you wish to discuss funeral arrangements?  Yes (complete below)  No (stop here)

**Pre-Planning Arrangements Made**

|  |  |  |
| --- | --- | --- |
| Name of funeral home |  | Interested Expressed by Family Members |
| Name of cemetery |  | Who expressed an interest: |
| Location |  | Name of person who will follow up: |
| Plot number & location of the deed |  | Date of follow up: |
| Location of contract pre-paid burial plans |  |  |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Living Will (if yes, indicate location of will): | | |  | |
| Organ Donation:  Yes  No | | | | |
| Additional Instructions: |  | | | |
|  | | | | |
|  | | | | |
|  | | | | |
| Name and address of lawyer: | |  | | |
|  | | | | |
| Name and address of clergyperson of choice *(if available):* | | | |  |
|  | | | | |

**Things to Do/Things to Expect:**

Know that every situation is different. The death or loss can sometimes be anticipated, but sometimes it is sudden and shocking. A strong recommendation is that you have some kind of plan. If your agency or you have not dealt with this before, there are several resources to call for help, such as:

Your Suoervisor of Case Management

Your DDS Director of Health Services;

Local Funeral Homes/Funeral Directors;

Hospice or other support groups;

Other Agencies who have dealt with this . . . .

**Make Future Plans:**

Call your local Department of Social Services (Title XIX) and ask for the worker assigned to the individual’s case to explain the different types of pre-planning arrangements. Irrevocable Funeral Contract is the best option. The individual can put aside any amount up to $5,400 and it won’t be counted as an asset. There are other types of Pre-Paid Funeral Funds, but these can be counted as an asset, cutting down the usual allowance of assets from $1,600.

Department of Social Services (Title XIX) has a limited amount they will give for burial arrangements. This will NOT cover the traditional funeral and/or burial services we usually see or desire for someone we care about. (The average cost for a funeral these days is between $6,000 - $7,000.) Generally, this will cover the expenses for a cremation, but not much else. If you desire other services, you will need to seek out people/agencies who will donate their time/facilities, etc.

**If you find out that someone you support has a terminal illness and you have the time to get prepared, here are some helpful hints:**

* Call the DDS Director of Health Services Call Hospice. Find out what they can do for the person you support, your staff/agency.
* Marshall any other resources that you can.

**THEN**

Make sure your agency nurse, the DDS Director of Nursing and the Hospice Nurse have a conference to help develop a plan of action. Involve the PST so everyone can pull together and the support plan will be comprehensive. Don’t anticipate that everyone knows what can or cannot be done. The rules do change a bit when this is the situation.

Remember that you have to support everyone. This will include people you normally don’t think of. Such as the day program staff and consumers/participants; friends who live in other group homes; former staff who may have a relationship, even if distant, etc. Involve people by letting them know what is happening and then it is up to them to decide how much involvement they can or want to have.

Everyone needs respect and support to get through this. Here are some things we found.

**Finds Ways to Take Care of Those People Who Are Doing the Direct Care in the House**

* People brought food over just to make sure the “care givers” were eating well. Sometimes they called first, but if we did not do this, we found care givers often postponed their own need to care for the ill person.
* The gatekeeper system worked well. It helped to have an objective person there to run interference, to provide emotional support or a venting post or just to feel there was someone else to step in with the ill person so the primary care giver could take a phone call, go to the bathroom or just have a break.
* Everyone should have a part to play and EVERY PART IS EQUALLY IMPORTANT! Give the care givers extra support. If the primary care giver is a manager, have another manager assume what responsibility they can to shift some of the burden. Meetings can be postponed or chaired differently. Ask your DDS Case Manager/Advocate/Team Leader/etc. to help out. If the primary care givers are regularly direct care, see if extra staff from other homes can work as extra staff on. Are there other friends/relatives/staff outside of the house who can help support the other housemates by doing outings, coming to visit or just talk on the phone.
* Determine the comfort level of the care givers/direct care staff. Some people will be comfortable working with the ill person immediately, but others may not ever feel so. It is just as valid and valuable for someone to want to work with the other housemates as to want to work with the ill person. We offered to let people transfer into other houses short term if it was too difficult for them to work in their normal position. We offered to move shifts or have additional staffing for those people who had to normally work alone. We also discussed the needs of the other housemates for consistency, but we respected the individual’s staff’s needs to make informed decisions about where they could do their best.
* Keep up with your paperwork. Keeping a journal is hard, but people wish they had done it in hindsight to remember all of the poignant memories and situations. We did start a journal of sorts called “Dorothy’s Memory Book”. This was appreciated and still is.
* Talk with the person. Despite the fact that the ill person has mental retardation, or if people believe that because of their functional level they won’t understand . . . THEY DO UNDERSTAND! You might be amazed at the insight that the ill person actually has. Work as a group to figure out what the person may say so you can have some answers you will be comfortable with. The person needs to hear the truth from you all. They need to hear it in respectful and supportive words. Not everyone can just spout these, so give people a “script” of responses. People will feel more prepared and comfortable and this will aid in helping the ill person feel supported and loved.
* Know when to step back. Don’t feel that you have to handle everything. You may be the most experienced or have the most information, but maybe you only think you do. EVERYONE has a need to be involved and recognized for their observations, their opinions, their needs. Let other people do things even if you have to point them in the right direction. Praise whatever they do. And you do not have to carry the weight of the world.

**Dying, Death, & Bereavement**

* Bereavement Resources
* <http://alpha.vaxxine.com/info/brvres.html>
* Includes FAQ\*\* and links to some of the resources listed in this pathfinder as well as many others.
* National Hospice Organization
* <http://www.nho.org/>
* Includes information about how to find a hospice, a hospice FAQ, discussion groups, and links to other resources.
* Caregiver and Bereavement Resources
* [http://hospice-cares.com/](http://alpha.vaxxine.com/info/brvres.html)
* Links to a variety of sites focusing on caregivers, bereavement, and hospice. Includes special resources for grieving children.
* Bereavement & Hospice Support Netline
* <http://ube.ubalt.edu/www/bereavement/>
* Resource directory providing a national (U.S.) listing of free or very low cost bereavement support groups, services, newsletters, and professional organizations and associations.
* Emotional Support Guide
* <http://asa.ugl.lib.umich.edu/chdocs/support/emotion.html>
* Provides organization for and links to Internet resources for physical loss, chronic illness, and bereavement.
* Helpful Essential Links to Palliative Care
* <http://www.dundee.ac.uk/meded/help/indexb.htm#secb>
* Focuses on communication throughout the dying, death, and bereavement continuum.
* DeathNET
* <http://www.islandnet.com/~deathnet/home_frame.html>
* Compilation of resources on dying, with an emphasis on death with dignity.
* Tom Golden’s Page: Crisis, Grief & Healing
* <http://www.webhealing.com/>
* Interactive site that includes “A Place to Honor Grief”, where individuals can submit personal narratives about their experiences with loss. Also focuses on men and their unique grieving process.
* Growth House, Inc.
* <http://www.growthhouse.org/default.html>