Friends…

While there is no way to prepare for the sorrow of losing a loved one suddenly, please know that our deepest sympathies are with you and your family during this difficult time and that we are here for your family.

You may have many questions about what to do and to whom you can turn for answers, so we have put together this booklet to help guide you through the next few days. It is meant to be a source of information for your immediate needs, as well a resource for support along your journey.
Funeral Arrangements

You can begin making arrangements for your loved one’s funeral when you leave the hospital. If you and your family have not used the services of a local funeral home in the past, you may wish to check with friends, clergy or other family members for suggestions. The Florida Cemetery, Cremation and Funeral Association has a list of Florida funeral homes on its website (www.ffda.org).

It may be helpful to have a family member or a friend accompany you to the funeral home as you choose the one that best suits your family’s needs. The cost of a funeral will vary according to the type of service desired, such as burial or cremation. If your family does not have the means to pay for funeral expenses, you may wish to contact your county’s health department and determine if it has an indigent burial program in place.

For families who are sending their loved ones to another country to be buried, the costs of transportation can be overwhelming. Be sure to contact the consulate or embassy of that country to determine if there are any assistance programs.

Death Certificate

The death certificate is an official document that will certify the cause and manner of your loved one’s death. It will be prepared by the attending physician at the hospital or the medical examiner and be given to the funeral director for completion. The funeral director then will file the death certificate with Florida’s Department of Health. Your family will need several, certified death certificates for all legal transactions and purposes where you must prove that your loved one has passed away.
The Medical Examiner/Coroner

The medical examiner (ME) will be involved if your loved one’s death occurred from an unknown cause, under suspicious circumstances or was considered unnatural. The ME will decide if an autopsy is necessary and also will give permission for organ donation to take place. The Florida Association of Medical Examiners supports organ donation and works closely with us to facilitate organ donation. Your LifeQuest coordinator will let you know if the ME will be involved.

If an autopsy is needed, it will be to determine the medical cause and manner of death. The cause of death is the reason why a person has died (stroke, blunt trauma, etc.). The manner of death is the circumstance in which the cause of death took place (natural causes, homicide, suicide, etc.). Another reason for an autopsy is to gather evidence for presentation in a court of law, in the event that is necessary. There is no charge for an autopsy when it is part of the ME’s investigation.

If an autopsy takes place, your loved one’s body will be brought to the ME’s office after the organ recovery operation. The ME will complete the investigation and release the body to the funeral home. The funeral director will work with the ME’s office to help you set the time and date for the funeral.
Financial Affairs and Insurance

Social Security: If your loved one was receiving Social Security benefits, notify your local Social Security office of the death, since these benefits must stop. If you are a surviving spouse, ask about your eligibility for increased benefits. Also ask about benefits that any minor children may be entitled to receive. If you are qualified to receive Social Security benefits, you must apply for them by contacting the Social Security Administration at (800) 772-1213 or online (www.SocialSecurity.gov).

Veteran Benefits: If your loved one was a veteran, you may be able to get assistance with the funeral, burial or other benefits. For information on benefits call the Department of Veteran Affairs at (800) 827-1000 or online (www.va.gov).

Crime Victim Compensation: If your loved one was a victim of a crime, you may be able to get financial assistance for medical bills, the funeral, the burial and grief counseling through Florida’s Division of Victim Services and Criminal Justice Programs. You can contact them at (800)226-6667 or online (www.MyFloridaLegal.com).

Health Insurance: Contact your loved one's health insurance company or employer to terminate his or her coverage while continuing coverage for other family members who may be named on the policy.

Life Insurance: Contact your loved one's life and casualty insurance companies. You will need to provide the policy number and a certified copy of the death certificate to file a claim. If your loved one is listed as the beneficiary on any other policy, arrange to have his or her name removed. Even if you do not feel up to this task right away, ask for help from friends or family so that you do not miss any deadlines for benefits.

Employers: If your loved one was working, contact the employer for information on pension plans or union death benefits. You will need a certified copy of the death certificate for each claim.

Credit Cards: If your loved one had credit cards, you will need to notify the credit card company and either cancel and return the cards or let them know that you, as the survivor, want to retain use of the card.

Bank Accounts: Arrange to change any joint bank accounts into your name. If your loved one’s estate is in trust, check with the bank or obtain legal counsel for the proper procedures to follow. If Social Security checks are set for automatic deposit, you will need to notify the bank of the death. Verify any debts and installment payments, including credit cards, mortgages, utility bills, etc., to ensure that bills continue to be paid.

Vehicles: If your loved one owned a vehicle, you many need to have the title transferred into your name. Contact the Florida Department of Highway Safety and Motor Vehicles at (850) 617-2000 or online (www.flhsmv.gov).
Checklists

Here are some checklists to follow over the next several days.

Before You Leave the Hospital:
❑ Ask the hospital staff to help secure your loved one’s belongings.
❑ Ask the hospital staff to help you obtain a lock of hair, or if appropriate, a photo of your loved one.
❑ Have a friend or relative take you home or meet you at home so that you will have support with the tasks ahead.

When You Return Home:
❑ Make a list of family, friends, employers, colleagues and your children’s teachers or principals who need to be notified of your loved one’s death through a telephone call.
❑ Have relatives, friends or neighbors help call those individuals and have them take turns answering your phone and greeting visitors to your home.
❑ Make an appointment at a funeral home to discuss your needs.
❑ Contact your clergy. If you need immediate assistance, invite him or her to visit you at home or let them know that you will be in touch soon about memorial plans.
❑ Gather information for the obituary. The funeral home normally will write the obituary for you and submit it to newspapers. They will inform you if there are any costs.
❑ Have someone keep a list of everyone who has called or stopped by with condolences, sent flowers or delivered food for your family.

When You Visit the Funeral Home:
❑ Arrange for childcare and pet care so that you may visit the funeral home without distractions.
❑ Bring your loved one’s name, date and place of birth, Social Security number, parents’ names, and if applicable, occupation and education.
❑ Bring a list of relatives and their relationships to your loved one.
❑ Bring a list of individuals who may wish to be pallbearers or speak at the service. The funeral home may be able to call them and let them know the details of the service.
❑ Bring the clothing in which you would like your loved one dressed for the service.
❑ Bring a list of special music or readings you would like at the service.
❑ Obtain extra, certified copies of the death certificate from the funeral director.
❑ Consider having food or a reception after the service. The funeral director can announce this after the service if you wish.
❑ Determine if you would like donations made to an organization or charity in memory of your loved one. This can be included in the obituary.
❑ Decide if you want to include in the obituary that your loved one was an organ donor.
❑ Determine if you will need someone to stay at your home during the funeral service to assure home security.
❑ Discuss what will be done with plants and flowers after the service (bring them home, donate to a church, hospital or rest home, take them to the grave site, etc.).
Over the Next Few Days:

- Coordinate special needs of the household such as childcare and carpooling, cleaning, grocery shopping, pet care, etc.
- Look into hospitality arrangements for visiting relatives and friends.
- Contact your bank concerning any existing accounts.
- Notify life insurance companies, creditors, credit card companies and automobile insurance companies of the death. You may need to have accounts transferred to your name.
- Contact your local Social Security office to report the death and to see if you are eligible for benefits.
- If your loved one was living alone, notify the utility companies and landlord. File a change of address card with the post office. Take precautions against theft.
- Locate your loved one’s will, notify the executor, and if needed, contact a lawyer. If there is no will, you will need to contact a lawyer to determine the next steps.
- Send acknowledgments after the service. Consult your list of those who brought flowers and meals, called and gave of their time.

Important Documents to Obtain:

- Death certificates (Certified copies can be obtained from the funeral director or Florida’s Department of Health or Bureau of Vital Statistics.)
- Social Security card
- Marriage certificate
- Birth certificate
- Birth certificates for each child, if applicable
- Insurance policies
- Deeds and titles to property
- Stock certificates
- Bank books
- Honorable discharge papers for veterans and/or a VA claim number
- Recent income tax forms and W-2 forms
- Automobile titles and registration papers
What is LifeQuest?
LifeQuest is the organization designated by the federal government as responsible for organ donation throughout northern Florida. We are called an organ procurement organization (OPO). LifeQuest is one of four OPOs in Florida and one of 58 across the United States. Our responsibility is to offer donation options to families whose loved ones have died and to honor the wishes of those who documented their intent to become organ donors.

Organ Donation
Whether your loved one made the decision to become a donor by joining the registry, or you made the decision as a family, you have supported something that is nothing less than heroic. In the midst of your tragedy and grief, you have given other patients hope for a renewed life through organ transplantation. You also have allowed something positive to come from your tragic and painful situation.

Organ donation allows your loved one’s vital organs, like the heart, kidneys and lungs, to be surgically recovered and made available to patients on the national transplant waiting list. Surgical teams will remove these organs during an operation, and within hours they will be transplanted into other patients who are suffering from life-threatening conditions. The surgical teams take great care to ensure that the donor’s body is treated with the utmost respect and dignity throughout the recovery process.

On occasion, we determine that organs cannot be recovered for life-saving transplant. They could have been damaged or shown signs of disease, or we may have been unable to identify recipients who were suitable matches for your loved one’s intended gift. If organ donation does not take place, we still will consider you among our donor families and continue to provide outreach to you.

Donation for Research
If an organ cannot be recovered for life-saving transplant, it is possible that donation for research can take place. Academic centers and research facilities can utilize organs to assist in the development of cures for diseases such as diabetes, Parkinson’s disease, Lou Gehrig’s disease and Alzheimer’s disease, or study what might be the causes of other diseases and conditions.
**Consent and Evaluation**

If your loved one made a decision or directive about donation while alive, such as joining a state organ donor registry or signing a donor card, you will not need to provide consent for organ donation. Your loved one already provided this permission.

If your loved one did not register a decision about donation, LifeQuest staff will discuss donation options with you. If your family supports donation, the next-of-kin will need to provide signed consent before the donation process can begin. Your LifeQuest coordinator will go through the consent form with you in great detail and will obtain medical and social information about your loved one. The purpose for these questions is to determine if his or her organs can be recovered safely for transplantation and ultimately save the lives of others.

After consent for donation has been documented, the LifeQuest team will perform various clinical tests, such as X-rays and labs, to determine which organs can be recovered for transplantation. While testing is being done, the donor must remain on the ventilator so that the organs remain viable for transplantation. This process may take a few hours, and you will be able to be at your loved one’s bedside periodically throughout this time.

While these tests are being performed, the process of matching the donor’s organs to the recipients will begin. This also takes a few hours, as several transplant centers may need to be contacted. After potential organ transplant recipients are identified, the tissue bank and eye bank will be called if your loved one also wanted to donate tissue and corneas. If the gift included donation for research, those programs will be contacted as well.

If your loved one experienced brain death, you and your family will have the opportunity to say your goodbyes in the intensive care unit before your loved one is taken to the operating room.

The transplant physicians and organ recovery teams will come to the hospital where your loved one is, and the recovery of gifts will take place in the operating room. Your loved one will be treated with respect and dignity during the entire donation process.
Brain Death

There are two ways of determining death: when the heart stops functioning or when the brain stops functioning. Most people understand that when the heart stops, death follows, because most people die this way. Not everyone understands what happens when the brain stops working first.

When someone has suffered a severe trauma to the head, such as an injury from an automobile accident, a gunshot wound or a stroke, the damage to the brain can be so severe that the person cannot recover. This injury can cause blood to stop flowing to the brain. When that oxygen-rich blood stops flowing to the brain, the cells of the brain die, including the brain stem, which is the portion that tells the body to breathe, cough, respond to pain, etc. When the brain and brain stem cease to function, the result is called brain death.

Most organ donors are on ventilated support at the time of their death, meaning that a machine is breathing for them and allowing their heart to beat. It may appear that a patient is sleeping, since the oxygen from the machine keeps the skin pink and warm, but once someone has reached brain death, they have passed. There is no way to restore brain function. The patient no longer can move, breathe, think or feel, and pain and suffering also have stopped. The machines no longer are providing “life support” and soon will be turned off.

Brain death is not the same as being in a coma or in a persistent vegetative state. Sometimes people confuse the term brain death with coma. Unlike brain death, when a patient is in a coma, some parts of the brain still are working, and the patient is alive. A patient in a coma might survive on a ventilator for a long time.
**Donation After Cardiac Death**

If your loved one has suffered a severe injury or critical illness from which there is no chance of survival, the hospital team will discuss end-of-life decisions with you and your family. Among these decisions will be if an advance directive is in place, which states ventilator support should be withdrawn. If there is an advance directive, you will need to discuss when to discontinue ventilator-support systems. This may be a very difficult conversation, and you may wish to include all of your family members in the process.

Only after you and your family have made the decision to withdraw ventilator support will you be offered the option of organ donation after cardiac death (DCD). Donation should not be considered as a factor in discontinuing support.

Donation after cardiac death may be an option for patients who have a neurologic injury and/or irreversible brain damage but do not meet the complete criteria for brain death. It allows them to fulfill their wishes to be organ donors. Unlike patients who have been diagnosed with brain death, these patients will succumb to cardiac death, which means the heart will stop working first.

You and your family, together with your LifeQuest coordinator and hospital staff, will decide where the ventilator will be removed. This process typically occurs in an operating room, but in some situations, it may take place in the ICU or in an area close to the operating room. Prior to the withdrawal of support, end-of-life comfort measures will be given to your loved one. These same measures would be given even if he or she were not going to be a donor.

Your family will be given time to say goodbye, and you can be present when the ventilator is removed. After the removal of the ventilator, the heart will stop beating, and a physician will declare cardiac death.

The recovery team will wait an additional five minutes before starting the recovery process. It is difficult to say exactly when the heart will stop following discontinuation of ventilator support. It could happen in a couple of minutes, or it may extend beyond an hour. If cardiac death has not occurred within one hour, donation no longer will be possible due to a decline in organ function. Your loved one will be brought to a patient room or remain in the intensive care unit for palliative care.
After the Donation

The organ recovery is the first operation to take place, as the organs will need to be transported to the recipients in a matter of hours. If tissue or cornea donation is to take place, those recovery teams will come to the operating room afterward.

When the recovery process has been completed, your loved one will be taken to the hospital morgue and then to the funeral home of your choice or the ME's office. If you wish, your LifeQuest coordinator can call you and let you know when the operation has been completed. The entire organ recovery process takes several hours and should not delay your funeral arrangements. Your family can begin making those arrangements at any time.

Your LifeQuest coordinator can give you limited information on the organ recipients who soon will be getting their life-saving transplants, such as their age, gender and region of the country in which they are being transplanted. You also will get a letter from your LifeQuest coordinator in approximately four weeks that will provide additional information on the transplant recipients, such as their hobbies and if they are married and have children.
The Next Steps

Losing a loved one is a painful and traumatic experience, and we want you to know that you are not alone in the grieving process. Whether your loved one was able to be a donor, or donation did not occur for medical reasons, we consider you one of our donor families, and you are welcomed into our family services program. Our staff is available to answer questions, offer support and provide referrals or resources as needed.

Not all families or individuals grieve in the same manner, and not everyone travels on their grief journey at the same pace. We understand that there is nothing we can do to take away your pain, but we do hope to support you in your healing. It may be much too soon to consider some of our outreach opportunities, but when you are ready, please consider if any of these activities would be helpful to you.

**Including donation in your memorial service:** If you would like to acknowledge that your loved one was an organ donor or make donor cards available at the funeral or memorial service, your LifeQuest coordinator can arrange this.

**Communicating with your loved one's organ transplant recipients:** Frequently recipients and donor families will want to write letters or exchange communication with each other. LifeQuest’s family services staff can send you a brochure that gives tips on how to get this letter started. We also will facilitate getting you any letters that the recipients might write to you and your family. Over time, we also can provide you with updates on how these individuals are doing.

**Making a memorial quilt square:** LifeQuest began a donor memorial quilt project in 1999, and today more than 300 families have created squares to honor their loved ones. We can mail you a packet on this special project. There is no timeline for the quilt, and you can make a square at any time.

**Finding the right support groups:** There are many local, statewide and national support groups and organizations created to help families who are grieving the loss of a loved one. We can provide you with a list of many groups, direct you to some wonderful resources on the Internet, and recommend books, articles and newsletters.

**Sharing the message of organ donation:** Many family members embrace donation and decide to share the message of life-saving donation and transplantation with others. There are many ways to do this, from personal advocacy to volunteer work.
Resources
Here are various support groups and informational sites that may be helpful to you in the weeks ahead:

For families of organ donors:
National Donor Family Council www.donorfamily.org
National Donor Memorial www.donormemorial.org
Donate Life Florida www.DonateLifeFlorida.org

For loss to suicide:
To locate support groups in the state of Florida www.FloridaSuicidePrevention.org
American Association of Suicidology www.suicidology.org
American Foundation for Suicide Prevention www.afsp.org
Survivors of Suicide www.survivorsofsuicide.com

For loss to violence or crime:
Parents of Murdered Children www.pomc.com
Mothers Against Drunk Driving www.madd.org
Office for Victims of Crime Resource Center www.ojp.usdoj.gov/ovc

For parents and children:
Compassionate Friends www.compassionatefriends.org
Bereaved Parents of the USA www.bereavedparentsusa.org
Sesame Street Workshop www.sesameworshop.org/grief
The Dougy Center www.dougy.org

For widows and widowers:
WidowNet www.widownet.org

General resources to help with grief and loss:
AARP Grief & Loss www.aarp.org/griefandloss
Beyond Indigo www.beyondindigo.com
Grief, Loss & Recovery www.grieflossrecovery.com
GriefNet www.griefnet.org
Journey of Hearts www.journeyofhearts.org

Other resources mentioned in this booklet:
Florida Department of Highway Safety and Motor Vehicles www.flhsmv.gov
Florida’s Division of Victim Services and Criminal Justice Programs www.MyFloridaLegal.com
Department of Veteran Affairs www.va.gov
Florida Cemetery, Cremation and Funeral Association www.ffda.org