Living with a Serious Illness

Learning that your illness is serious and may limit your life is never easy and can impact every part of your life. You may experience new emotions or have spiritual questions upon hearing the news. As your illness evolves you may also notice new physical changes. By learning what to expect and knowing about your options, you may feel more in control at this difficult time.

The following are some changes you may experience.

**Emotional**
- Fear – of what will happen as your illness progresses, or about the future for your loved ones
- Anger – about the change in diagnosis; about past treatment choices
- Grief – about the losses that you have had and those to come
- Anxiety – about making “the right” decisions and facing new realities
- Disbelief – about the illness and changes that will be taking place
- Relief – in knowing what your illness is and being able to decide on future care
- Loneliness – because you feel different from your “healthy” friends and family members

**Physical**
- You may tire easily, have difficulty participating in your regular activities
- Changes in sleep – you may feel exhausted, or have difficulty sleeping
- Renewed energy, if your treatments change and your symptoms are controlled

**Spiritual**
- A deeper sense of faith
- Questioning of your faith beliefs
- Exploring the meaning of your life; wondering what your legacy will be
- A new understanding of or focus on spirituality that did not previously exist

**Practical Considerations**
- A desire to take care of legal and financial matters
- A fear about how others will do what you have always done for your family or at your job — this may include a need to teach others what you know
- A need to gather information from healthcare professionals, the Internet and others about your illness, care options and experiences of others
- Concern that your wishes and choices for care are known and respected
Myths and the Truth

There are myths that exist around serious illness. Learning more can help you and your loved ones cope with this new phase of your life.

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<th>MYTH</th>
<th>TRUTH</th>
<th>REMEMBER</th>
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<td>Accepting that this illness cannot be cured means that “nothing more can be done.”</td>
<td>When the focus shifts from cure to care, a great deal can be done to relieve physical pain and emotional suffering, and to ensure a good quality of life.</td>
<td>Learn about care and support options early on, before your care needs change. Hospice and palliative care offer quality medical care to manage pain and other symptoms and provide support to you and your family.</td>
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<td>People go through emotional “stages,” when diagnosed with a life-limiting illness, and end up “accepting” their situation.</td>
<td>You will face a wide range of emotions over time; you may feel some of the emotions listed in the beginning of this flyer, or none of them, and in no particular order.</td>
<td>All of these feelings are real; there is no “right” way to feel. You may find support by talking with others who are facing similar situations, through books, through your faith system or within your network of family and friends.</td>
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<td>Dealing with a serious illness brings spiritual strength.</td>
<td>For some, facing a serious illness will deepen their personal sense of faith and spirituality, or challenge them to question beliefs. Others may not experience any change with regard to spirituality and faith.</td>
<td>Thinking about spiritual issues is very common when coping with a serious illness. Don’t be afraid to reach out to your spiritual leader or faith community for help or support.</td>
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<td>People give up control and are usually uncomfortable as the illness progresses.</td>
<td>You can have a great deal of control over what you want and don’t want as your disease progresses. With planning, you can ensure that your wishes are known in case you can no longer express them.</td>
<td>Have conversations with your loved ones about what you do and do not want. Designate a healthcare agent to speak for you in the event that you can no longer speak for yourself.</td>
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<td>Talking honestly about a serious illness with family and friends is difficult for everyone involved.</td>
<td>While these conversations are never easy, dealing with the illness according to your background and beliefs can bring a sense of relief.</td>
<td>Hospice and palliative care professionals can provide information and emotional support for you and those who care about you.</td>
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What You Can Do

Facing a change in prognosis or news of a serious illness brings challenges and tough decisions. It can also bring opportunities to:

- Look at the ways that you have coped successfully with difficulty in the past
- Think about what you want and what you don’t want for end-of-life care
- Learn about care options like hospice and palliative care
- Examine your priorities and values, and share them with those you love
- Communicate your wishes, hopes and fears with loved ones
- Take tangible steps, such as signing advance directives, to ensure that your wishes are followed and your family is supported
- Maintain control and dignity throughout the process

For more information:

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National Hospice and Palliative Care Organization