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Center for Healthy Aging Ministries, Programs & Services

FROM THE CHAMPS PARISH NURSE



Living with Chronic Illness

The Diagnosis

What is chronic illness?

A chronic illness results in a long-lasting health condition that will require ongoing treatment and human adaptations. Chronic diseases or conditions, except in the case of those caused by trauma, have a slow course of progression that may be punctuated with periods of stability. A few examples of chronic illnesses include diabetes, arthritis, fibromyalgia, cancer, COPD (chronic obstructive pulmonary disease), and AIDS. In reviewing this short list it is evident that not all of these are immediately life threatening but left unmanaged or over time these illnesses can be life changing or life-ending.

Living with a long lasting sickness (also known as a chronic illness) elicits all types of responses not only in the affected individual but also in those he/she interacts with. As with all human behavior this situation sets in motion a number of dynamics that may create challenges for the individual and require multiple changes and compassionate understanding from those providing support.

Learning of a Diagnosis

When first being told you have a chronic diagnosis a whole host of emotions can envelop you--shock, disbelief, denial, anger, rage, sadness, unloved, abandonment by God, confusion, vulnerability and the list goes on. There

is no right or wrong feeling. One important response you can have is to find someone who will listen to how you are feeling. They do not need to have all the answers, but they should have a listening ear and a compassionate heart.

Once you hear a word like cancer, asthma, diabetes or anything else of this magnitude, you simply may withdraw into yourself and not be able to process and understand what is said. This is a type of protective response where the mind shut down temporarily as a protective mechanism. Therefore, asking a spouse, family member, trusted friend, neighbor or the parish nurse to accompany you to the doctor is a way to have two sets of ears listening for what is said. Additionally, it is often necessary to plan a follow-up visit with the health care provider to have your questions answered and the treatment plan re-explained. Before going for a follow-up visit or for subsequent appointments take the time to organize, prioritize and write down your concerns then be prepared to go over the most important issues first. No question is stupid or too trivial to be asked! Medical jargon (terms) can be confusing and the treatment plans are sometimes complicated and should be given both verbally and in writing. Understanding self-care management is critical to identifying and stabilizing your individual

needs and minimizing future problems and /or progression of the illness. Furthermore, you need to be aware that not all your symptoms may be related to the chronic illness, as you are still going to have all the usual challenges, such as “flu”, “common cold”, appendicitis and so forth.

During the initial phase of an illness family and friends rally around with support and this can be overwhelming, depending on the type of diagnosis. This is especially true in trauma or a life threatening illness. It would be nice if a simple formula existed for handling one’s emotions, but emotions fluctuate and can be different from day to day. All illnesses have some type of losses— physical, relational, financial and possibly spiritual. Sometimes the severity of the illness requires concentration on the immediate healing of the individual and the full implications of the emotional, social and financial impact occurs later.

Although sending cards and staying in touch are important ways to support, friends and family can do other practical things such as offer to baby sit, do grocery shopping, help with transportation of siblings to and from school, drop off family meals; and, offer assistance with transportation to and from therapy. As appropriate to the circumstances, think of something wacky to do to cheer the individual up; or, simply sit and listen quietly while they share their feelings.

An individual may come to be viewed by themselves and by others as a “cardiac”, a “diabetic, a “cancer” patient, an illness. Everyone with any type of chronic illness is still an individual with dreams, aspirations and a life! Albeit

the approaches to achieve the goals they set may need to be adapted to the current circumstances, but it is still important to set goals, have plans, revise them as needed and move ahead.

Managing Everyday Life

Body

Loss of function regardless of the disease that causes it -- heart, arthritis, respiratory diseases (asthma, chronic obstructive pulmonary disease (COPD)), and others all result in changes in self-care needs that require problem solving skills to manage symptoms, find community resources, develop or modify social support and handle day to day activities. Sometimes you’re uncertain about when to call your health care provider. A good rule of thumb is to check with your physician whenever severe, persistent or new symptoms arise.

Fatigue, low energy and sleep disturbances are common with many, if not all conditions of a chronic nature. Problem solving involves taking the responsibility to keep a daily journal of symptoms and associated contributing factors. Keeping track of the duration and the immediate or delayed response associated with daily activities undertaken is important to planning for needed changes in the daily schedule or treatment plans that will alleviate the degree of fatigue, effect on sleep and /or the pain produced. An examination of this journal data can help pinpoint causative factors and lead to creative solutions. The following is an example of the data you could maintain. Additional tracking would depend on the type of diagnosis:

Use the following rating scales to evaluate your day:

Fatigue: Rating Scale: (1=None, 5= Moderate 10= Exhausted)

Sleep Rating Scale: (No Sleep =1, Fair= 5, None= 10)

Pain Rating: 1= Low 5= Moderate 10 =Intense

For pain, also record the prescribed or over-the counter medication taken, dose used, and degree of relief obtained.

Date(s):	Type of Activity:	Duration of Activity:	Fatigue Level:	Sleep Rating:	Pain Rating:

An examination of the data could lead to: planning a rest period or nap before doing the activity that precipitates pain; limiting the number or length of time of an activity is scheduled; doing prescribed exercise regimens to strengthen muscles and foster endurance; taking a prescribed pain medication or anti-inflammatory before doing the activity that precipitates the pain; switching to an evening shower or tub bath to help lessen muscle tension before going to bed; using heat or cold therapy; and, using assistive devices properly. Sleep disturbances can be alleviated by decreasing caffeine intake and by creating an environment conducive to sleep with the right temperature, ventilation and a quiet atmosphere. The use of relaxation techniques or guided imagery before bedtime is helpful for some individuals.

Pain can be physical and emotional.

It is imperative to understanding pain symptoms which demand immediate medical attention such as the warning signs of a heart attack or stroke. On the other hand, some diseases such as arthritis or back pain require you to balance your physical activity, fatigue and rest. Prescribed exercise of the correct type and amount for maintenance of endurance, flexibility and joint function can have a profoundly positive effect on arthritis and back

conditions. Keeping a log and sharing it with the health care provider of the pain experienced, medications used and degree of relief obtained can be helpful in evaluating the effectiveness of all prescribed interventions (medications, physical therapy, heat, cold, electro-stimulation, etc.). You have to take charge of self-monitoring and reporting for a regime to be established that will have maximum benefits for your needs.

Not all chronic diseases require you to have outside assistance but changes within the immediate family may be necessary. In some instances, hiring in-home help to do housework or assist with personal care may be an option. Generally, a home health agency maintains listings of persons with different skills who can be hired for a fee. The fees vary widely depending on the skills desired, licensing of the caregiver and the additional charges for bonding, taxes, Social Security and a profit for the agency. Hiring someone directly may be cheaper, however you need to check credentials carefully and obtain recommendations if electing to do this. Additionally, your physician may make referrals to community resources. The local visiting nurse association is also a good first contact when seeking an evaluation of your individual needs.

Being a family caregiver can be physically and emotionally exhausting.

Ask your physician, the visiting nurse association, parish nurse, churches in the community, or organizations such as the American Cancer Society where resources are available in your vicinity for the care givers' use such as a day care center for the family member or a support group for care givers to attend for their personal restoration.

The Emotional Impact

Mind

Everyone has a body, mind and spirit connection and although the first step may be to understand and meet one's physical self-care (body) it is imperative that the mind and spiritual needs also be addressed to maintain personal balance. A chronic illness of any type affects more than the individual with the disease or disorder, it also impacts all those who connect with them. Each person, the one with the chronic illness and the support persons, have feelings about why this has happened, what caused this, how to cope with it as well as fears or resentment towards the changes this brings in their lives.

Living with a chronic illness elicits all types of responses not only in the affected individual but also in those he/she interacts with. As with all human behavior this situation sets in motion a number of dynamics that may create challenges for the individual and require multiple changes and compassionate understanding from those providing support.

Communication is critical to all relationships, but it becomes imperative when faced with a chronic condition. In the months and years after a diagnosis is reached living with intermittent or constant limitations requires creative solutions and the assistance of support persons. It is important to learn how to ask for help, to say "no" in some circumstances, word requests tactfully,

and recognize verbal and non-verbal styles of communication.

Asking for help isn't easy, but it doesn't mean you are a failure. Not making your needs known and thinking your support persons instinctively know your wants is unrealistic. One positive step to meeting the individual's identified needs can be to hold recurring family meetings to establish creative, unified approaches that allow everyone to cooperatively plan and implement the solutions. Being part of the process makes it easier to "volunteer" to assist. It may be that you only need assistance intermittently when pain is severe, but sharing your feelings in a positive, constructive manner can help others to understand your obstacles and overcome them. On the other hand, the care givers also have feelings that need to be shared and honored.

Taking the time to word requests in a thoughtful manner will require you to couch your words carefully while examining not only your feelings, but those of others. It is not only what you say but how you say it that imparts a message. Avoid giving the impression that you are a victim and others "have to" respond to your wishes. Always listen for what is being said and not said in a conversation.

Saying "No" tactfully is an art you can learn. Letting people know when you have a sudden onset of pain, fatigue or other circumstances that precludes your participation helps them to understand you are not rejecting them personally nor being thoughtless about the use of their time and efforts. If you're saying "No" because of physical limitations such as a mobility issues, try collaboratively to explore alternative approach and then decide if there is a solution to the problem. Realistically, there are times you are not interested in doing something and that's alright, too.

Stress, anxiety and isolation are also struggles. Identifying the causative factors for stress can help with finding the solution or ways to lessen it. When limitations exist it is necessary to look for alternative ways to accomplish tasks you did previously with ease, but now find challenging. Being anxious, especially when your life requires intermittent or constant adjustments can be exhausting. Likewise, having to depend on others for assistance can create feelings of weakness and failure. This can result in self imposed isolation. On the other hand, some instances of isolation are related to a need for transportation but an unwillingness to ask for someone to drive them.

Planned treatments such as chemotherapy, surgery, kidney dialysis, or radiation all produce stressors—uncertainty of outcomes, changes in personal appearance, decreased strength and endurance. In these cases isolation may be from the need for rest. However, this is also an opportunity for a church visitation program to actively monitor the individuals need for outside support or assistance.

Emotions often surface at unexpected times and there is no right or wrong schedule or place for expressing them. Many times people try to camouflage their true feelings to protect those close to them or because others they encounter expect them to have resolved their anger, frustration or outrage at having their life changed dramatically.

Getting into a support group with others who have similar conditions is an important step. Contact your local hospital, doctor's office, library, check local newspapers in the health section, call the visiting nurse association or contact churches to find support groups that meet in your community. The internet also can provide a wealth of information on a particular disease or disorder and many national agencies

also sponsor local support groups. Once you locate a support group don't expect to find all the answers in one brief meeting. Attend several group meetings before reaching a conclusion about how much "help" they'll be to you in your situation.

Depression can occur from a number of causes. Regardless of the triggers, and there can be multiple causative factors—loss of control over your life, self care, job, finances, physical function and others. Indicators that it may be necessary to seek professional assistance include feeling overwhelmed, depressed, uninterested in life and events, disinterested in personal care and grooming, having suicidal thoughts, and/or losing the ability to make decisions. It is important to seek help and not turn to alcohol, illicit drugs or self harm as the solution. Some medications also have the side effects of giving you a "down" feeling and therefore discussing your feelings with your physician is important. You may need a medication adjustment or change.

The Spiritual Journey

Spirit

Everyone wants their personal experiences to have meaning and their lives to have a purpose. This occurs through our understanding of us, our connection to others and the community and to events (art, literature, music) as well as to a higher being.

All of us seek some degree of involvement with others and a continued outreach for hope, acceptance, forgiveness, love and the ability to express our emotions openly.

Faith

During and following the diagnosis of a chronic illness emotions fluctuate and swing on a pendulum. Anger and sadness may escalate into blaming

God, circumstances, and others. Sometimes in our anger we shout to the Lord, "Why me God?" My life is disrupted; I cannot do _____, _____, or _____. This can easily evolve into doubt of God and his goodness. "I am in profound pain, Lord. Are you listening? If not, why not." It is alright, sometimes helpful, to share those feelings with God in prayer. The book of Psalms is full of such prayers. We try desperately to decide if we can survive with the changes in our life. On the other hand, depending on the circumstances and diagnosis we may feel great gratitude to be alive. While some cry out in anger, others hold steadfastly to their belief that God is with them no matter what circumstances they face and they are unwavering in their belief. A faith foundation can be a great asset, and even grow, during a difficult season of life.

Those around can pray for healing and although miraculous physical healings do occur, sometimes they do not. However, not all healing is physical and this is something that isn't often stressed. Prayer can provide comfort, nurturing, love, compassion and relief of emotional suffering. Prayer knows no limits within the boundaries of God's control, but the control is God's and not ours and that is where the faith walk may become challenging for some individual.

Loss of any kind is painful. We need nurturing during this time. The support of family and compassionate friends, neighbors and the church is a gift. They can provide an antidote for the pain we feel. Love is nurturing. Strength to face each day is required. It is difficult to admit that the love, strength and endurance we have could be support from time in daily prayer with God. Not a cure for the disease we want, but an indication that He has not left us. "I have been crucified with Christ. It is no

longer I who live, but Christ who lives in me. And the life I now live in the flesh I live by faith in the Son of God, who loved me and gave himself for me."
-Galatians. 2:20

Hope

During a prolonged chronic illness the individual gives up hope for a cure and starts to focus on hope for a better quality of life, for friends, for others to stay in contact, for acceptance with whatever limitations they have. They want a place at God's table to feel loved, prayed for, involved and still be able to participate in church, communion, Bible studies and to continue to serve others within their limitations. Participation in the community of God's people helps them remember that God is still there. They want to be surrounded in love and not rejected, isolated, forgotten and abandoned.

Therefore it is imperative that the church look at whether they stay connected with persons who fall away due to physical or mental limitations. Is the church handicap accessible, are there barriers to being able to worship, do we offer to help and become involved in providing support to the individual and family. Do we offer to hold a Bible study at their home so they don't have to struggle to attend? Can they still sing in the choir, or is access to do this restricted by physical barriers. Or, as frequently happens does the individual fall "off the radar"?

"Now faith is being sure of what we hope for and certain of what we do not see." -Hebrews 11:1.

Trust

There are periods in life when trusting others is difficult, but with adversity we are faced with multiple opportunities to trust others with helping to meet our daily needs whether they are physical, emotional and/or spiritual. Although God may not grant physical healing,

illness can impart profound spiritual healing. It's not about us and our requests; it's about faith in God. This concept is not easily accepted nor understood. We learn to pray fervently for our needs and wants and react favorably when our prayers are fruitful. Yet sometimes we pray and pray and despite long hours and repeated pleas our requests see to go unnoticed. A sense of abandonment can be felt and simultaneously anger for God's lack of response. We have grown accustomed to asking God and receiving; perhaps the ultimate test of faith is asking and accepting God's promise for salvation and eternity not for an easy life filled with continued daily joy.

*I am like an olive tree
flourishing in the house of God;*

*I trust in God's unfailing love
for ever and ever.
I will praise you forever for what you have
done;
in your name I will hope, for your
name is good.
I will praise you in the presence of
your saints.
-Psalm 52: 8-9*

Regardless of where a person is on the "faith walk" love them, nurture them and accept them as God's creation in His image. Healing is a slow process whereby an individual is gradually transformed from introspection to a greater potential as a person who has known fears, grief and loss and perseveres towards experiencing peace, hope and love with a profound acceptance of the love of the Savior.

Resources:

Kate Lorig, R.N., PhD., Halstead Holman M.D., et al. (2006). Living a Healthy Live with Chronic Conditions. Boulder, CO: Bull Publishing Co

Web:

http://www.livingweithillness.com/id10_m.htm

<http://www.alpineguild.com/COPING%20WITH%20CHRONIC%20ILLNESS.html>

http://www.kidshealth.org/PageManager.jsp?dn=KidsHealth&lic=1&ps=207&car_id=201

<http://www.biblegateway.com/passage/?search=2%20Corinthians%201:9-11>

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