SANOFI GENZYME

Living Well with a Chronic Condition:

Quality of life where every day matters

careconnect PSS®
Personalized Support Services

What you'll find inside?

- What it means to live well with a chronic condition.
- How to cope with diagnosis and manage everyday life.
- How to get on a path to well-being.
- How to create and make the most of your support system.
- Some resources to support you along your journey.

This booklet is a tool for you to create a personal action plan and to start a discussion with your doctor or your family and friends. It includes a worksheet at the end to guide you in creating your own action plan.

Princeton,

living with Pompe Disease

What “living well” means

An analysis of scientific papers over the past 20 years shows that a precise, clear, shared definition is a long way off. Observations about “living well” and quality of life suggest that it encompasses the following:

- **Life satisfaction,** which is subjective and changes.
- **Multidimensional factors** that include everything from physical health, psychological state, level of independence, family, education, wealth, religious beliefs, a sense of optimism, local services and transport, employment, social relationships, housing, and the environment.
- **Cultural perspectives, values, personal expectations, and goals of what we want from life.**
- Not just the absence of disease but, the **presence of physical, mental, and social well-being.** The need for multidisciplinary medical teams who can develop a perspective on psychosocial needs and not just physical care.
- **Our interpretation of facts and events,** which helps to explain why some people with a chronic condition can report an excellent “quality of life” while others cannot.
- **Our level of acceptance of our current condition**, and our ability to regulate negative thoughts and emotions about that condition.

How a person views his or her well-being or quality of life.

- Multidimensional and includes all aspects of life:
  - Physical.
  - Psychological.
  - Emotional.
  - Social.
- Subjective and can mean different things to different people:
  - » Depends on your personal views, which are influenced by a number of factors, including:
    - Genetic.
    - Environmental.
    - Psychological.
    - Developmental.
- May be improved by addressing specific goals and plans to manage your physical and mental health.

Lecita,

living with Pompe Disease

Chronic conditions impact quality of life

People living with a chronic condition face unique challenges and stresses that can affect quality of life.*

PHYSICAL

- pain
- fatigue
- sensory issues
- trouble sleeping

EMOTIONAL

- fear
- guilt
- anger
- shame
- hopelessness
- uncertainty
- disconnection or numbing
- giving up

SOCIAL

- family interactions
- friends
- community
- caregivers
- isolation
- ability to communicate
- finance

PSYCHOLOGICAL

- depression
- anxiety
- obsessive compulsiveness
- phobias

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*These are only examples. You may not have all of these, and you may have other challenges as well.

People just diagnosed with a chronic condition may grieve the loss of their health and previous life and may go through a process of grieving for themselves and for their family.

- Grief is a **normal** and **natural** reaction to loss.
- Grief varies from one person to another, from one culture to another, and also changes over time. It's **subjective** and based on the impact the loss has on one's life.
- Grieving is a **complex reaction** with emotional, physical, behavioral, cognitive, social, and spiritual aspects.
- Grief is **personal**, but also **shared** among family members and loved ones.

Nick,
living with
MPS I Disease

> Getting a diagnosis or being at risk for a chronic condition may mark the end of a previous known world and a transition to a new unknown one. Sometimes, it can be a relief to finally get an answer or a diagnosis (a name) for your symptoms.

The grieving process

- Following loss, a grieving process can end in an acceptance of the diagnosis and a willingness to make the most of life in spite of the condition.
- The grieving process is different for everyone and doesn't occur in any specific order. People often move between these different general stages of grief.

» **Denial:**

A person is unwilling to accept the diagnosis; ignores symptoms and medical test results; may refuse treatment; may try to maintain a previous standard of life or activity.

» **Anger:**

A person has accepted the diagnosis as real but feels a strong sense of unfairness in the situation; may become angry, irritable, frustrated bitter, or hostile.

» **Bargaining:**

A person has moved past the sense of unfairness and has a temporarily renewed sense of hope; may try to reason with doctors and other medical professionals about a cure or get involved with research; may try to make deals with God or another higher power.

» **Depression:**

A person stops bargaining and reasoning and has lost any revived hope; enters a period of extreme sadness and hopelessness and wants to be left alone.

» **Acceptance:**

A person finally accepts the diagnosis and develops coping strategies to learn to live with and adapt to his/her condition; willing to offer support and encouragement to others.

“Meaning” is central to the grieving experience

- People are naturally motivated to find meaning and purpose in their lives in spite of suffering.
- Some people cope by finding meaning in their diagnosis.
- Finding meaning and purpose can help with the news of a diagnosis for both the individual and the family or loved ones.

These stages are not intended to be a rigid framework that applies to everyone.

You do not have to go through each stage in order to heal. Some people resolve their grief without going through any of these stages. And if you do go through these stages of grief, you probably won’t experience them in a neat, sequential order, so don’t worry about what you “should” be feeling or which stage you’re supposed to be in.

There is no typical response to loss, as there is no typical loss. Our grieving is as individual as our lives.

How a person copes with grief can affect well-being and quality of life

DENIAL VS ACCEPTANCE

Denial:

- Some people may ignore their diagnosis or risk for a chronic condition as a way to lessen anxiety. This can delay needed support and lifestyle changes.

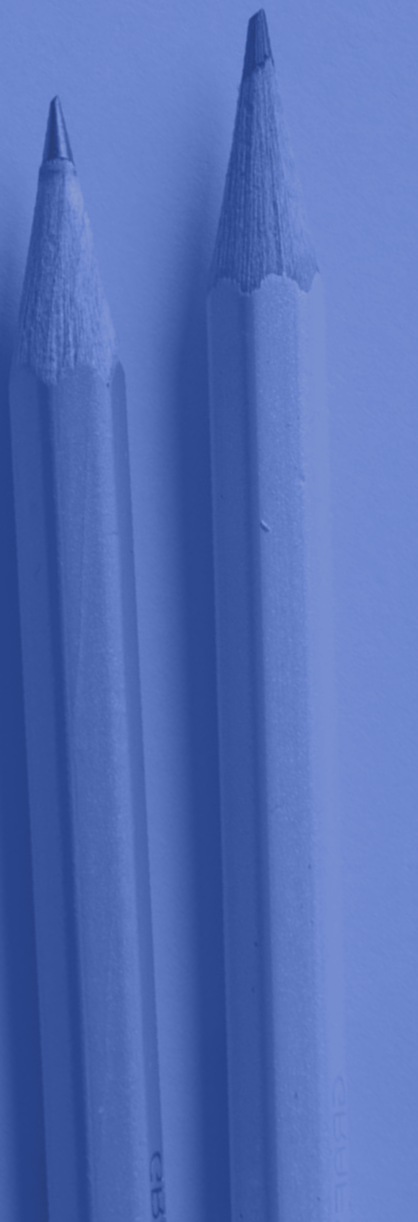
Acceptance:

- Accepting a diagnosis can be challenging but freeing. It's the first step toward healing and reaching inner peace. Accepting your diagnosis can allow you to seek help and support.

ANGER can either motivate someone to work to feel better or drive people away who want to help. Self-management strategies can help to regain control and reduce uncertainty.

BARGAINING can usually be accompanied by guilt. People may think that something they did contributed to their illness. No one has control over their genes, and illness is not a personal failure. Regardless of what happened before, you now have control of how you manage your condition.

DEPRESSION is a response that lessens further stress by shutting down. If it lasts, it can lead to despair and inactivity. Self-help techniques and professional guidance can help nurture productive thinking.



Depression, Anxiety, and Loneliness

People living with a chronic condition are generally at higher risk of depression and anxiety, particularly right after diagnosis.

Depression:

- Feelings of hopelessness and helplessness.
- Things that used to be enjoyable aren't fun anymore.
- Low energy levels, and nothing seems worth the effort it requires.
- Hard to fall asleep and stay asleep.
- Aches and pains are felt more deeply.
- Hard to concentrate.

Anxiety:

- The reaction to stress.
- Fear and anticipation of impending danger, catastrophe, or misfortune.
- Physical symptoms of tension: tense muscles, rapid breathing, and increased heart rate.

Loneliness:

- A deep sense of emptiness, worthlessness, and lack of control.
- Can lead to an increase in symptoms of depression and also in stress, anxiety, and anger.
- Having even one personal connection can help.

10 Suggestions

for coping with anxiety and depression:

1. Therapy is important, even short-term.
2. Practice relaxation techniques.
3. Make sleep a top priority. A good night’s rest is a mood stabilizer.
4. Do things that bring you joy.
5. Do any type of movement/physical activity.
6. Hope is an integral part of coping and finding meaning in a diagnosis.
7. Talk about anxieties, uncertainties and fears, losses and sadness.
8. Connect with others. Hearing another voice is a form of connection. Even small talk can promote happiness.
9. Plan a way to manage your condition and set short, manageable goals.
10. Limit your online world to more positive information that makes you feel safe and connected.

Create a circle of support

Seek support and connect with others:

- Healthcare team
- Mental health professionals
- Friends/social networking
- Employer

Good communication may help improve health and quality of life.

- Communicating with your loved ones, your care team, your peers, and your employer is important.
- It may be difficult to talk about your condition, but if those around you understand your needs better, they can offer support. Let them know what they can do to help.
- Communication should have a clear purpose:
  - A problem that needs to be solved.
  - A point that needs to be made.
  - A sharing your experience, insight, or wisdom.
- Communication increases your ability to persuade, motivate, influence, and get along.

Florence,

living with
Gaucher
Disease

Suggestions for communicating your needs

- Successful communication should:
    - Be uncomplicated.
    - Be specific.
    - Use some repetitions.
    - Check for understanding.
- Discussing your needs with your doctor:
    - Make a list of your concerns.
    - Write down questions ahead of time.
    - Take a friend or family member for support and as another listener.
    - If your questions or concerns are not addressed, ask how you can contact them to further your discussion.
- Tell your loved ones how they can help:
    - Childcare.
    - Meal preparation.
    - Transportation.
    - Food shopping.
    - Chores .
- Ask if your employer can make reasonable accommodations:
    - Flexible hours.
    - Working from home.
    - Job share.

Luke,
living with
Fabry Disease

Caregivers can suffer physically, mentally, and socially, too.

For example:

- Physical symptoms (headaches, stomachaches).
- Isolation.
- Depression and anxiety.
- Anger and resentment.
- Guilt.
- Stress of decision-making.
- Loss of personal time.

Supporting a loved one with a chronic condition can be just as challenging.

12 Suggestions for caregivers to manage their stress:

1. Connect with support groups and therapy.
2. Establish a support network of family and friends who want to help. Don't think that you should have to handle the responsibilities on your own.
3. Know you cannot be perfect.
4. Set realistic expectations for yourself and your loved one.
5. Learn to say "no" to things you cannot do.
6. Identify your stressors and your coping skills.
7. Surround yourself with things that inspire joy, happiness, hope, and encouragement.
8. Educate yourself about the condition.
9. Take care of yourself by eating healthily, getting plenty of sleep, exercising, and doing activities you enjoy.
10. Explore relaxation techniques.
11. Take a moment in nature. Getting away can remind you that there is a world outside. Taking a break is a necessary step in taking care of yourself so that you can care for someone else.
12. Self-care can come in many forms and each can help address the signs and symptoms outlined. Important to attend to your physical care and your emotional and mental health.

Getting started on a path to well-being

Individuals have their own unique ways of coping to improve quality of life. A therapist can help provide you with tools and strategies for managing stress, depression, anxiety, or grief. Here are some tips that can also help you get started:

Regain control and be your own best advocate by **learning as much as you can about your condition.** Empower yourself through knowledge and raise awareness among others.

Listen to your body and mind.

Identify challenges to gain better control and self-management.

Understand your **coping process.**

Self-care and self-compassion

A. Treat yourself with kindness and understanding:

- Helps to lessen anxiety and depression
- Promotes healthy behaviors (movement, eating healthily)
- Positive thoughts fuel our ability to handle everyday stress

B. Have a "Self-Care Arsenal" and do things that you really enjoy, like watching a favorite movie, reading a favorite book, or listening to a favorite song.

Write down your thoughts, feelings, frustrations, or concerns. This can help you keep track of your moods or behavior over time.

Reframe your thinking. As difficult as it may be, try to look for the good in times when you are stressed and overwhelmed. Counter negative thoughts with positive ones. At the root of some therapies is the understanding that our thoughts influence our emotions, which in turn influence our behaviors. If you feel yourself spiraling into imagining worst-case scenarios, stop and put your mind elsewhere.

Make a list of people you can always count on and reach out to. This will help you to feel that you're not alone.

Take baby steps and set achievable goals.

Seek help if you feel overwhelmed and self-help isn't enough. Look for a psychologist or other mental health provider who can help you learn how to manage your stress effectively.

My roadmap to well-being

QUALITY OF LIFE

1. What does well-being and quality of life mean to you?

2. List the things that contribute to your well-being and quality of life,and rate them by importance using numbers (with 1 being the most important)

☐

☐

☐

☐

☐

Which of the things you listed above are the most important for you to maintain or improve on?

Rewrite it here!

COPING WITH GRIEF

3. How did you feel when you first found out you were at risk for/or diagnosed with a chronic rare condition?

4. How are you feeling now?

5. What things may help you get through challenging times?

FINDING SUPPORT

6. What are some things others could do to help?

MY ACTION PLAN

7. The parts of my well-being that I want to:

Prioritize	Ways I can do this:
Maintain:	Ways I can do this:
Improve:	Ways I can do this:

8. Limitations and challenges I have because of my chronic condition:

- o Things I can reasonably keep doing:
- o Things I can do differently to address them:
- o Things that I might have to stop doing:

9. Things I enjoy that can help me cope:

- o Something I would enjoy starting:

10. Benefits that accepting my condition may have:

- Things that would help me to accept it:

11. Goals for myself:

Small goals:	What can help me reach that goal:
Bigger goals:	What can help me reach that goal:

12. Who do I want to include in my support system? What can they do to help?

Name:	What they can do:
Name:	What they can do:
Name:	What they can do:

- Reasonable things my employer can do to help:

13. Questions to ask my doctor during my next visit:

ROADMAP TO WELL-BEING FOR CAREGIVERS

1. How did you feel when your loved one was first diagnosed?

2. What do you find most challenging about caring for your loved one?

3. What do you think could help lessen your load?

TIPS TO GET STARTED

Connect with support groups/social media

Ask other family members to share the load if possible

Exercise, go for a walk, or try relaxation techniques like yoga or meditating

Set aside time for yourself! Invest time in a hobby or something you enjoy

MY ACTION PLAN

4. Others that I (and my loved one) can rely on for additional support:

5. What can others do to help?

6. Self-care I can practice to help relieve my stress:

How your CareconnectPSS team will support you

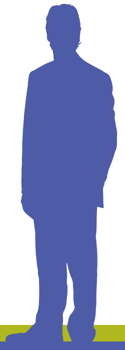
CareConnectPSS — Personalized support services for patients

CareConnectPSS®, personalized support services for patients, represents Sanofi Genzyme's more than 35-year commitment to supporting the rare disease community. CareConnectPSS is designed to support each patient's unique journey.

Our range of support to help patients living with a rare disease includes:

- Programs such as the Copay Assistance Program and Charitable Access Program for eligible patients
- Disease-specific information, including genetic education
- Care coordination for treatment
- Dedicated CareConnectPSS Patient Education Liaisons and Case Managers

Depending on your individual needs, your CareConnectPSS Team of experts can assist with the following:



Your **Case Manager** offers expertise in health insurance, navigating the health care system, facilitating transitions which may impact your access to insurance or treatment, and can assist you in identifying resources to help manage out of pocket costs related to your treatment.

Your **Patient Education Liaison** can help educate you, your family, friends, teachers, or employers about your disease.

To learn more about our range of support offerings, or to reach your existing CareConnectPSS Case Manager:
Call **1-800-745-4447 (Option 3)**
Email us at **Info@CareConnectPSS.com**
Visit **www.careconnectpss.com**

Additional resources

For more information on Medicare coverage and enrollment:
Visit the official Medicare website: **www.medicare.gov**
Visit the Social Security website: **www.ssa.gov**
Talk to you employer's human resources department or office administrator

Rare Diseases Organizations

- In addition to your CareConnectPSS Support Team, the following organizations can provide additional resources related to your rare disease
    - **National Society of Genetic Counselors**
      https://www.nsgc.org/
    - **National Organization for Rare Disorders**
      www.rarediseases.org
    - **Genetic Alliance**
      http://www.geneticalliance.org/
    - **Global Genes**
      www.globalgenes.org

Psychologist Locator

The Psychologist Locator lets you consider many factors in searching for psychologists, including their areas of specialization, gender, insurance accepted, languages spoken and much more. From the American Psychological Association.

https://locator.apa.org

*Another tip for finding a mental health provider. Look on the back of your insurance card. There should be a contact number for mental health provider. Call that number and ask for a mental health provider within your network. The pdf link will explain this process.

https://www.apa.org/helpcenter/parity-guide.pdf

Cheryl,
living with
Pompe Disease

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BY YOUR SIDE

through your journey with a rare disease

JUST A PHONE CALL OR EMAIL AWAY

Whether your needs are large or small, your CareConnectPSS team will work closely with you and your family to ensure you receive the confidential and personalized support you need. To learn more about our range of support offerings, or to reach your CareConnectPSS Case Manager, please call **1-800-745-4447**, and select **Option 3**, or email us at **Info@CareConnectPSS.com.**

For more information, visit us at **www.CareConnectPSS.com.**

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