
Quality Of Life

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Quality of Life: What does it mean?

Are you living well? . . . really living? Or are you simply surviving, letting the disease make you a couch potato? What is your quality of life? Do you have fun, smile or laugh a lot, enjoy life, feel you are accomplishing something? Do you have a full and satisfying life . . . with family, friends, travel, hobbies, volunteer work?

This is the first in a series of articles about Quality of Life for renal patients, aimed at help you to lead an enjoyable life. First, let's loosely define two concepts:

Quality of Care -- QOC has to do with the medical aspects of your health. It includes the care you receive from your doctor and nursing staff, as well as how well you take care of yourself.

Quality of Life -- QOL has to do with your attitudes and how you spend your time when you are not receiving treatments.

Both QOC and QOL are very important and contribute to how well you live. QOC comes first. You have to become as medically healthy as possible. So, be sure you are getting quality of care.

The medical community has several ways for you to monitor your QOC – namely your "numbers" (KT/V, URR, etc.). If your numbers are not as good as they should be ask your doctor how to improve them. Keep a monthly chart, so you can determine how well you are measuring up.

Another aspect of your medical health is how well you follow doctor's orders. Are you taking your medications and following your diet?

A third aspect is your knowledge of the disease. Educate yourself. Don't be afraid to ask questions. In other words, take charge of your medical condition. Take responsibility for your own care.

Next, look to your QOL. Survival alone is not enough. Demand more from yourself than just surviving. You need to enjoy an acceptable level of daily living, a new lifestyle. Ask yourself what things are important to you? What keeps you going? What activities did you enjoy before renal failure? You can keep doing these things with a little planning.

Make a list of your values, the things that are important to you. Some values are suggested in the accompanying checklist.

Use these as thought-starters as you develop your own list. Next, set realistic, achievable goals for each value. Be as specific as possible. For example, for "family," a goal might be to spend frequent quality time with them. You could:

- take twenty minutes a day talking with your children
- take a vacation this summer with the kids
- plan get-togethers with your son's family the second Sunday of each month
- or take time to do some of the things that you and your spouse enjoyed before renal failure.

Make plans to achieve your goals. Talk about them with your spouse, family, social worker, close friend, or anyone else who supports you. A word of caution: don't let others dissuade you if your goals are realistic. Have the courage to ask for their support as you try to improve your lifestyle. Finally, put your plans into action. Go for it!

Work toward each goal gradually. For example, if your goal is to walk three times a week for one-half an hour each time, start slowly -- maybe just up to the corner and back. Gradually add more distance and more time to your walks.

Your attitudes are very important. You can consider yourself disabled and lead a depressed,

sedentary life. Or, you can consider yourself lucky to be alive and live life to its fullest. Changing your habits means that you will have to change the way you think about things. You may have to change what motivates you -- becoming fit versus staying inactive. You may have to shift priorities -- taking a walk instead of watching TV.

In other words, you have to rethink your lifestyle. Determine what changes you want to make. When you set goals that are internally and personally meaningful, it is easier to motivate yourself to achieve them. Be positive. Yes, you have a kidney disease. But medical treatments have extended your life. Do something productive with this new lease! Be glad you have plenty of non-treatment hours to schedule as you wish.

Quality of Life Action Plan

- Make a list of your values and priorities.
- Set realistic, achievable goals for each value.
- Make plans to achieve each goal.
- Put your plans into action, gradually working toward each goal.

What Values Are Important To You?

Activities of Daily

Living

- Eating
- Grooming
- Bathing
- Dressing
- Toileting

Family

- Quality time daily
- More, better communication
- Help with homework
- Frequent family outings
- Intimacy

Physical Fitness

- Stronger legs
- Stronger arms
- Flexibility, coordination
- Endurance

Home Management

- Cooking
- Laundry
- Shopping
- House cleaning
- General repairs
- Gardening
- Major projects
- Workshop projects

Friends, Social Life

- Card games
- Parties
- Get-togethers
- Movies
- Concerts

Church

- Weekly services
- Choir
- Committee work
- Study groups

Hobbies

- Bread baking
- Fishing
- Stamp collecting
- Sewing

Education

- Renal disease
- Physical fitness
- Lifestyle changes
- Current issues
- Personal interests

Recreation

- Ball games
- Swimming
- One-day get-away's
- Evening entertainment
- Museums

Travel, Vacation

- Touring
- Visiting relatives and friends
- Attending renal conferences

Back to Work

- Part-time employment
- Full-time employment
- Volunteering

Other

- _____
- _____
- _____
- _____

It's not what happens to you that matters as much as what you do about it afterwards!

Positively alive!

Kidney failure causes stresses and frustrations that are very real, sometimes even very difficult. It is easy to get caught up in them, to let them ruin your daily life. However, you are free to choose positive attitudes over negative ones. You are free to choose a better life.

This second article presents you with several suggestions to help you improve the quality of your life.

Dealing with problems

Keep your problems in perspective. Renal failure is not the end of the world. Be glad things are not worse! Instead of letting any problem take control of your attitudes, the trick is to take control of the problem.

Don't dwell on what you can't do. This only leads to more stress. Instead, look at the problem realistically and work on finding a solution. Then accept the outcome. You did the best you could.

Getting out of the rut

If you have more negative thoughts than positive ones, you are in a rut and are going nowhere. The rut affects not only the way you feel about yourself, but also the way you look at life.

To climb out of the rut, you need to change your negative attitudes into positive ones. For example, instead of "My life will never be the

same," think positively: "My life will be different, but I will work to make it better."

Another way to climb out of the rut is to list the positives in your life and your life concentrate on them. For example, you have four days a week without dialysis. You have a loving family, a comfortable home. Work on being happy with these positives.

Also, just talking to others can make you feel better. Your family, friends and social worker all can help you talk through the rough times. Ask them for their support and their cooperation as you work to improve the quality of your life.

Building your self-esteem

Self-esteem means truly loving and valuing yourself. You accept yourself as you are, while you still work to improve yourself. You have a healthy appreciation for yourself, your best qualities, and your achievements.

Building your self-esteem can be the single most important thing you can ever do for yourself. Consider it to be one of the building blocks upon which you can change your attitudes, change what needs to be changed, and have a greater sense of peace and security.

The best thing about self-esteem - it's available to everyone. Everyone can have a healthy self-image! Have pride and confidence in yourself. Work on reflecting a strong, vibrant, energized person.

Don't be your worst enemy. Instead, give yourself a break. Lighten up. If you don't like how you see yourself, redefine yourself. Use "Your Personal Attitude Inventory" to describe the new you.

Another method of building self-esteem is to look your best. How you look has a great deal to do with how you feel. So, change your appearance -- comb your hair, put on makeup, update your wardrobe, sit up straight, and most importantly, smile.

Then smile some more, because optimism is contagious. People around you will be caught up in your happy appearance and will become more positive toward you.

Giving yourself time to change

Allegedly it takes 21 days of conscious effort to replace an old habit with a new one.

Start by taking an inventory of your negative attitudes now. (Use "Your Personal Attitude Inventory.") Work on replacing them with positive ones. Visualize the new you. Daydream about you with positive attitudes. Rehearse in your mind how you will react to upcoming situations.

Review your successes each day, giving yourself credit for little improvements. After a month, take Your Personal Attitude Inventory again, checking your progress.

One month to a happier you.

- Take an inventory of your current attitudes.
- Define the new you -- the attitudes you would like to have.
- Work on each attitude, improving your self-image. Visualize the new you.
- Each day give yourself credit for successes. After a month, check your progress against YPAI worksheet.

Your Personal Attitude Inventory

For each of the following positive and negative attitudes, circle the number that defines yourself as you are now. Then go back with a different color of ink and circle how you want to be, in other words, how you want to improve certain attitudes. Work on a few of these. In a month, review your progress. Use the following scale: 1 = Never 2 = Rarely 3 = Sometimes 4 = Frequently 5 = Always

Negative Attitudes

For negative attitudes, the lower the number the better. Improve attitudes with higher numbers.

Bored	1	2	3	4	5
Cold	1	2	3	4	5
Critical	1	2	3	4	5
Cruel	1	2	3	4	5
Cynical	1	2	3	4	5
Dissatisfied	1	2	3	4	5
Drab	1	2	3	4	5
Dull	1	2	3	4	5
Exhausted	1	2	3	4	5
Fearful	1	2	3	4	5
Frustrated	1	2	3	4	5
Guilty	1	2	3	4	5
Helpless	1	2	3	4	5
Hopeless	1	2	3	4	5
Hostile	1	2	3	4	5
Inconsiderate	1	2	3	4	5
Ineffective	1	2	3	4	5
Inferior	1	2	3	4	5
Irritable	1	2	3	4	5
Lonely	1	2	3	4	5
Pessimistic	1	2	3	4	5
Rejecting	1	2	3	4	5
Resentful	1	2	3	4	5
Rude	1	2	3	4	5
Unhappy	1	2	3	4	5

Positive Attitudes

For positive attitudes, the higher the number the better. Improve attitudes with lower numbers.

Accepting	1	2	3	4	5
Appreciative	1	2	3	4	5
Cheerful	1	2	3	4	5
Competent	1	2	3	4	5
Confident	1	2	3	4	5
Considerate	1	2	3	4	5
Courageous	1	2	3	4	5
Courteous	1	2	3	4	5
Energetic	1	2	3	4	5
Enthusiastic	1	2	3	4	5
Excited	1	2	3	4	5
Friendly	1	2	3	4	5
Growing	1	2	3	4	5
Happy	1	2	3	4	5
Helpful	1	2	3	4	5
Hopeful	1	2	3	4	5
Kind	1	2	3	4	5
Optimistic	1	2	3	4	5
Patient	1	2	3	4	5
Peaceful	1	2	3	4	5
Productive	1	2	3	4	5
Relaxed	1	2	3	4	5
Secure	1	2	3	4	5
Sincere	1	2	3	4	5
Understanding	1	2	3	4	5
Warm	1	2	3	4	5

Exercise for the Health of it!

One of the common side effects of kidney failure is muscle wasting. You tend to lose your strength and endurance. Your kidney disease causes part of this. But a big part of muscle wasting is under your control. You are probably far less active than you used to be. You have lost muscle mass due to inactivity. In other words, if you don't use them (muscles), you lose them.

An exercise program is your way to turn yourself around, to reactivate those muscles and build them up anew. This article has several suggestions to help you start an exercise program and improve the quality of your life.

In this third article in this series, we will turn our attention to exercise and how it can improve your strength and endurance.

Benefits of Exercise

Frequent exercise can help you in many ways. You will look and feel better. You will enjoy increased energy, lower blood pressure, and stronger muscles. Also you may sleep better, maybe even lose weight.

shortened and tight. Stretching relaxes the tightness, allowing your muscles to become flexible again.

Start with easy stretches of your arms and legs. Hold each stretch for 10 to 20 seconds. Repeat three times.

Types of exercise

The three general types of exercise are stretching, aerobics, and strength training.

1. Stretching

Stretching improves the flexibility of your muscles and improves your coordination. When you do not use your muscles for a long period of time, they become

2. Aerobics

Aerobic exercise involves continuous activity of your large muscle groups. Walking and swimming are good examples. These exercises get your heart and lungs pumping.

Start with only 5 to 10 minutes of gentle walking or swimming. Gradually build up to 20 or 30 minutes, 3 or 4 times a week.

Be consistent. You lose the gains from aerobic activity fairly quickly when you stop.

3. Strength training

Strength training, also called resistance exercise, builds muscles and increases their strength. Two common forms are lifting weights and exercising in the swimming pool.

Start easily. Choose a weight that you can lift 8 times without becoming fatigued -- perhaps a can of soup for arms, a pair of heavier shoes for legs. Do 3 sets of 8 lifts.

Gradually increase the number of lifts until you reach 15 lifts. Then add more weight and begin again with 3 sets of 8 lifts. Lift and relax slowly. Exhale as you lift, inhale as you relax.

Don't let your knees or elbows lock in an outstretched position. Keep them slightly bent.

Begin and end each exercise session with gentle exercises, such as stretching. Your muscles and heart need these warm-ups and cool-downs as they switch from regular daily activities to a workout, and vice versa.

Getting started

First, talk to your doctor and get approval to start an exercise program. Then, set up a program that will work for you. Here are some guidelines.

- Choose exercises that you enjoy doing.
- Exercise a minimum of three days a week. If you exercise every day, alternate between aerobics and strength training. Your muscles respond to this alternating pattern better than if you did the same type of exercises every day.
- Exercise with a friend, or at least share your daily successes with someone. Keep each other motivated to stay on the program.
- Start slowly. Don't overexert yourself. Gradually add more time, more effort.

An exercise program can help you become fit. In general, start slowly, progress gradually. This allows your body to adjust to your changing activity levels.

As you design your program, remember three things :

-
- Frequency

Exercise at least three days a week. Work up to a daily routine, if possible.

- Intensity

The trick is to work hard enough but not too hard.

The best rule is to listen to your body. Exercise to a level that you would describe as being a comfortable push. If you feel pain, you are pushing too hard.

For aerobics:

Your heart should beat faster. Your breathing should be faster too. But slow down or even stop if you begin to pant or feel nauseous.

Take the talk test. You should be able to talk as you exercise. If you are breathing too hard to talk, you are exercising too hard.

For strength training:

You should be able to lift a weight at least eight times (repetitions). If not, choose a lighter weight. Within ten minutes after stopping aerobics or strength training, your breathing should be normal.

After one hour, you should feel normal. If not, slow down the next time. Your muscles should feel like they have done work. However, they should not be so sore that you cannot exercise the next day.

- Time

Start your regular routine with the length of time that is comfortable -- perhaps only five minutes of walking.

As you build up your muscles and endurance, gradually add more time, more intensity.

Work toward exercising for 30 minutes at a time, 3 times a week. Of course, you can exercise for a longer period if your body and time permit.

Stop exercising if:

- If you begin to feel sick, stop exercising immediately.
- If you feel very tired, are short of breath, are dizzy, or have leg cramps, stop immediately.
- If you feel an irregular or rapid heartbeat, get sick to your stomach or have chest pain, stop immediately.

Putting it all together

Following is a general program to get you started. You may change this to suit your own body's needs.

M-W-F

Stretch arms and legs for a total of 2 to 3 minutes (a warm-up).

Then walk for 10 minutes.

Finally stretch for 2 to 3 more minutes (a cool-down).

T-Th-S

Stretch arms and legs for a total of 2 to 3 minutes.

Then lift weights for 10 minutes.

Finally stretch for 2 to 3 more minutes.

Sunday

Rest.

Don't just sit.

1. Pick a routine and stick with it.
2. Start slowly.
3. Gradually add more time, more intensity.

Your life is yours to enjoy

Now we will address your social side--that part of you that enjoys being with family and friends and having a good time. Even though you are a kidney patient, you can enjoy life.

So be happy. Be satisfied with yourself and your life.

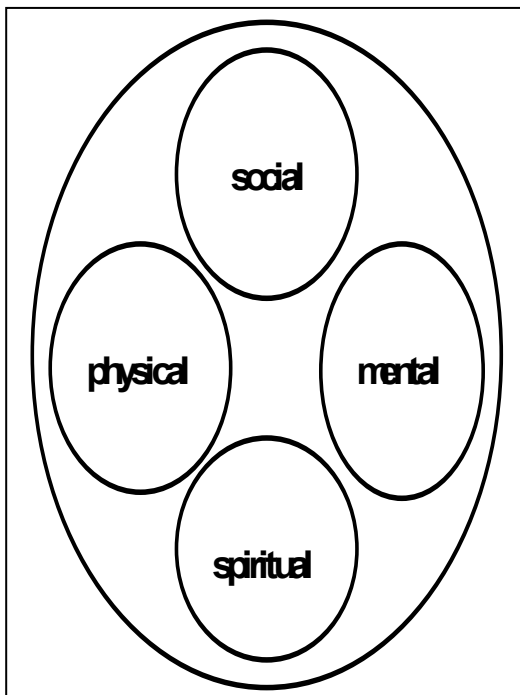
This article is the fourth in a series of Quality of Life.

Finding the balance

You are a total person. Yes, you have a physical side that is sick. But you also have a social side, a mental side, and a spiritual side.

Being well and feeling well involve your total person with all of its dimensions.

Take charge of your total self, and become fully alive. You deserve it.



The dimensions of your life

Enjoy your family and friends

You have had many wonderful times with your family and friends. You still can, regardless of kidney disease!

Think about spending quality time with your loved ones. They are part of your life and contribute a lot to your feeling of happiness. Tell your family and friends what they mean to you. Keep these relationships alive and part of your "fun" and "love" lives.

Plan your social life around those you want to be around. Plan with them such activities as frequent family outings, holiday get-togethers. Plan to go to parties, movies, and concerts. Organize some card games.

The list of fun activities is up to you. Include the things that make you happy.

Return to your hobbies (or get new ones)

What did you like to do with your spare time before kidney disease? Fish, sew, collect salt shakers? Good. Keep doing these things to the extent that you are able.

Hobbies are a creative way to reward yourself. You like spending time with your hobby, and this helps to relieve stress. More importantly, hobbies help to put a smile on your face. They make you feel better. In return, the people around you respond to your smile and return a happy face to you. Life immediately becomes brighter. So get out of the house and be active.

What do you like to do for recreation? Is it ball games, swimming, hiking, and dancing? Do it! Don't sit at home and wait for the fun life to come knocking on your door. Instead, go out. Do things. Get active again doing the things that give you a renewed spirit and drive.

How long has it been since you've been to the museum, zoo, or other local places? It's time to go back again. Enjoy a few hours and renew an interest.

Travel, take a vacation. Renal failure does not mean the end to

traveling. You just have to plan ahead and have your social worker arrange for you to dialyze somewhere else. Of course, hemo patients can take one-day trips or weekend trips without arranging for dialysis. PD patients can take their daily supplies with them.

Suggestions for travel include:

- Visit relatives and friends.
- Take a one-day trip. Consider one-day group tours that furnish the bus, the meals, and the activities.
- Take a one-week vacation in the USA. Ask your social worker to set up dialysis for you.
- Take a cruise.
- Go to a conference for kidney patients and bone up on the latest.

The place and length of trip are up to you. Enjoy yourself.

Go to church or join a study group. Don't forget your head and your spirit. We all need to re-energize ourselves. Decide what is important to you, and get involved. Perhaps you want to rejoin the choir. Or maybe you want to take an adult education class in some topic that interests you.

Regardless, spend time making you feel complete as a person.

Planning your social side

Use this worksheet to help you put a greater emphasis on your social life and on having fun.

Family

- Quality time daily
- More, better communication
- Help with homework
- Frequent family outings
- Intimacy
- Holiday get-togethers

Church

- Weekly services
- Choir
- Committee work
- Study groups

Friends, Social life

- Card games
- Parties
- Get-togethers
- Movies
- Concerts

Hobbies

- Fishing
- Sewing
- Collecting
- Scouts

Recreation

- Eating out with family and friends
- Ball games
- Swimming
- One-day getaways
- Evening entertainment

Museums Travel, Vacation

- Touring
- Visiting relatives and friends
- Attending kidney conferences

Getting started

- Look at your weekly calendar. Cross out times for dialysis, exercise, sleep and any other standing activities.
- Look at the time you have remaining. This is your time to spend as you wish.
- Make a list of the things you would like to do. Include the activities you enjoyed before becoming sick. Include some new ones too.
- Make plans to fill your leisure time with these activities.

RENAL REHABILITATION: A Holistic Concept

Previously we have looked at several different aspects of rehabilitation: quality of life, quality of care, mental attitudes, physical fitness, exercise and most recently the social part of life.

This, fifth and last, article will try to place the pieces together to make it whole.

What is Rehabilitation?

Rehabilitation means restoring the whole person.

In the case of a person with renal disease it may mean restoring an individual to the previous level of functioning or, encouraging a person to remain as independent as possible.

The individual may be able to perform all the activities of daily living such as bathing, dressing and cleaning. Also important to functioning as a whole person are independent activities of daily living such as shopping and handling one's finances.

You may not be able to perform all of these activities or be able to perform some of them with help.

But, there is type of functional rehabilitation that can help you to lead a fuller and more productive life.

It may include programs that improve exercise tolerance and stamina, encourage and demonstrate ways to increase independence, and accept more personal responsibility.

Another type of rehabilitation, vocational rehabilitation, refers to employment, either full or part time. These programs are geared toward gaining employment or retraining for new types of jobs.

Vocational rehabilitation may include a work hardening program, community based work simulation, selective job placement and long term follow up or mentoring program.

Regardless of what type of rehabilitation, there are certain components that are commonly found in all programs.

These were first identified by the Life Options Rehabilitation Advisory Council (LORAC). They are considered to be essential ingredients in any rehabilitation effort. They are as follows.

Encouragement

Individuals with renal disease need to be encouraged to look at rehabilitation in a positive way.

You need encouragement from family, staff members and friends in order to restore your life and make the most of yourself. You can also form peer groups, become a volunteer or join organizations for renal patients.

Staff members can help by providing optimal dialysis, provide flexible times and schedules, reinforcing your self-care efforts and offering encouragement.

Family and friends can help by supporting your efforts at rehabilitation through verbal encouragement, stressing good renal nutrition, and attending meetings with the family member.

Education

You need to learn about your illness, the effects of treatment, and become aware of your responsibility in the treatment.

You can do this by seeking out and reading educational materials on kidney disease and the treatment options, asking questions to clarify or seek out additional information. You can learn about ways to adapt to the physical and mental changes that kidney disease brings.

Always be sure that you are getting adequate dialysis and learn more about the role you play in adequate treatment.

Learn how to take care of your access and what signs or symptoms to report to your health care team. Seek out members of your care team to talk about strategies for successful adaptation.

Staff members can help you by explaining the physical changes that occur and ways to decrease their effect. They can provide early pre dialysis education and continued educational programs for you and staff members, with an emphasis on ways to achieve greater independence.

Family and friends can accompany you to programs to provide support and learn about the disease and read printed information provided.

Exercise

You can consult with members of the care team and together create an exercise routine that can be followed easily. You can read information provided on exercise for renal patients.

Make it your responsibility to do your exercise routine as often as possible on a regular basis to maximize your health and well being. Be creative and try different types of exercise until you find the right combination.

Staff members can help by encouraging you and creating simple exercise programs to be done during or before dialysis.

Staff can also provide a Physical Therapy referral if needed and point out other patients who have been successful at exercise.

Family and friends can help by encouraging you, and perhaps participating in the exercises. They can learn more about successful programs for renal patients by finding and reading information.

Employment

If possible retain your current employment status or seek retraining to do other types of work, such as vocational rehabilitation programs.

Seek out selective job placement services to help you improve your chances of finding a job. Find out what is available in the community to help you.

If employment is not possible try part time employment or look at volunteering in your community on a regular basis. You can also go back to an old hobby or develop a new one to enrich your life.

Staff members can refer you for vocational rehabilitation and inform you about incentive programs available.

Staff can help to educate potential employers of renal patients and point out successful examples of other working patients.

Family and friends can encourage your efforts toward employment. They can help you to investigate opportunities and programs and make adjustment in the home to facilitate a return to work, volunteering or developing new hobbies and interests.

Evaluation

This involves recognizing how far you have come and looking at your evolving needs to see if you need to change things a bit. It means keeping tabs on your progress and making corrections if they are needed. Look at how you are functioning compared to a few months ago.

Find new things to try if you are not satisfied with your progress. Set new goals or change old ones.

Staff members can help you by using several of the functional tools available to monitor your progress. They can provide various rehabilitation services to meet your needs. Staff can also look at what has been done and if it worked and then revise the plan to suit your specific needs.

Family and friends can help to look at how well you are functioning and try to find new and fun ways to improve your level of rehabilitation.

They can suggest new ideas to try or new ways to do things. These are five very important components of rehabilitation for renal patients. As you can see every one has a part in the 5 E's of Rehabilitation, but the most important player is YOU.

A human being is very complex and made up of multiple and unique parts that when taken together make up a whole person, a holistic person.

The concept of rehabilitation helps you live up to your potential, to your expectations of yourself despite your chronic disease. It has many parts and components and they all serve to make you a holistic, functioning human being.

It's really up to you to seize the opportunities.

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