

Nothing **IS** Impossible



Live life

on your own terms

A **HealthToday** Special Edition for People on Dialysis

HealthToday

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Message from the Chairman, Board of Directors National Kidney Foundation of Malaysia

It gives me great pleasure to pen a few words for the publication on “Nothing Is Impossible – Live life on your own terms”, a *HealthToday* Special Edition for people on dialysis.

Firstly, thank you very much to CCM Duopharma Biotech Berhad for initiating this publication especially for the kidney failure patients in Malaysia. The National Kidney Foundation of Malaysia is honoured to have a sponsor that is as dedicated as you and we are proud to be part of this auspicious publication. Your effort to educate and assist kidney failure patients in Malaysia is indeed commendable.

NKF currently has approximately 1,600 dialysis patients receiving subsidized dialysis treatment in 26 dialysis centres nationwide, and the numbers are growing annually.

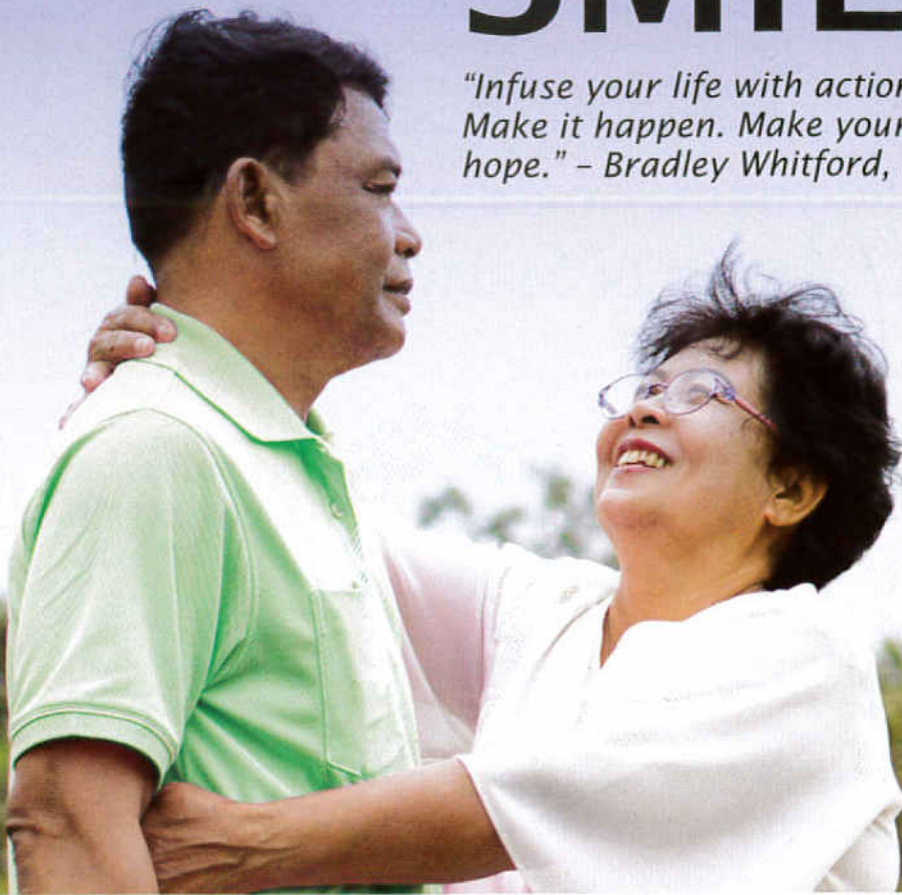
On behalf of the National Kidney Foundation of Malaysia, I would like to thank each and every one of you for contributing towards this publication and making this project a reality for the patients on dialysis. I am confident that this publication will provide answers to many common questions from the patients and their care givers and enable them to manage their treatment to the best of their ability.

Thank you very much once again. Your trust and continued support inspires us to carry on doing what we do best, providing dialysis care to poor patients and educating the public to take care of their kidneys.

Dato' Dr Zaki Morad Mohd Zaher

YOU CAN KEEP SMILING

"Infuse your life with action. Don't wait for it to happen. Make it happen. Make your own future. Make your own hope." – Bradley Whitford, actor and political activist



If you have chronic kidney disease (CKD), it means that your kidneys have been damaged. To date, we have not found a cure for CKD. However, we have medications that can slow down the progression of your CKD, allowing your kidneys to still function for as long as possible.

What do my kidneys do?

Your kidneys perform many important functions. The main ones include:

- Removing wastes and potentially harmful substances from blood
- Removing excess water in order to maintain your body's fluid balance
- Helping your bone marrow to produce new red blood cells
- Regulate certain hormones, including those that help to keep your blood pressure under control

If your GFR falls below 15, it means that your CKD has reached a stage where 85% to 90% of your kidney function is gone. This is no longer enough to keep you alive. Don't worry, another type of treatment will be offered to make sure that you can still keep going.

What are my options?

There are two options that can be considered:

YOUR KIDNEY NUMBERS

If you have CKD, two sets of test values, often called 'kidney numbers' will become important. They are used by your doctor to determine how much kidney function you still have left.

- **Albumin to Creatinine Ratio (ACR)** – you will supply a urine sample to the laboratory, where it will be tested for a substance called albumin.
- **Glomerular Filtration Rate (GFR)** – your doctor will measure the level of a substance called creatinine in your blood, and calculate the GFR using the result, your age, your weight and your sex.

- *Kidney transplantation.* Your surgeon will implant a new kidney from a suitable donor into your body. Following this, you will have to take medications regularly to prevent your body from rejecting the new kidney. You can discuss this option further with your attending kidney specialist or nephrologist.
- *Dialysis.* There are two types of dialysis available: haemodialysis and peritoneal dialysis. You will find out more about them in the next chapter.

I still have so many things that I want to do.

And you may still be able to do them. There is no cure yet for kidney failure, but if you keep up with your treatment, there is a possibility that you will still be able to live a fulfilling life.

This booklet contains information and tips to help you achieve your wish. So, please keep reading. With some hope and determination, as well as some adjustments to your lifestyle and diet, you *can* keep living ... and smiling.

KIDNEYS



UNDERSTANDING DIALYSIS

"Few things in the world are more powerful than a positive push. A smile. A world of optimism and hope. A 'you can do it' when things are tough." – Richard DeVos, entrepreneur and businessman

What does dialysis actually do?

Dialysis keeps you alive. When you have kidney failure, your kidneys are unable to remove waste and extra fluids from your body. Dialysis is a treatment that steps in to perform this function. There are two types of dialysis.



HAEMODIALYSIS

Your blood will be passed through soft tubes and filtered via a dialyser in a dialysis machine. The dialyser acts like an artificial kidney to remove wastes and potentially harmful substances from your blood. Usually, you will visit a haemodialysis centre to receive this treatment about three times a week. Each time, treatment lasts for three to four hours.

PERITONEAL DIALYSIS

This is a daily treatment that can be done at home. A surgical procedure will first be done to attach a tube-like structure called a Tenckhoff catheter into your abdomen. Through the catheter, a blood-cleansing solution called dialysate will be channelled into your peritoneal cavity. It will remove wastes, excess fluids and potentially harmful substances from your blood.

Which treatment is most suitable for me?

Your healthcare provider will help you determine which one is best for you. Aside from your condition, there are also other factors to consider, and both treatments have its advantages and disadvantages.

HAEMODIALYSIS

Advantages

- Allows you to be in contact with healthcare professionals (doctors, nurses) who can also watch out for any problems you may have.
- You may also meet other dialysis patients and support one another emotionally.
- You only have to go for treatment a few times every week.

Disadvantages

- You may feel tired after treatment.
- You will need to plan your working hours, travel, etc around your dialysis schedule.

PERITONEAL DIALYSIS

Advantages

- Flexibility. You can do it at home (or at any clean place), and you can also do it while traveling or asleep.
- You can do it on your own.

Disadvantages

- Some people may find it hard to carry out the procedure correctly.
- There is a risk of infection in the peritoneal lining (peritonitis) if the procedure is not carried out properly.
- Treatment has to be done every day, so some people may experience 'burn out' quicker than those undergoing haemodialysis.

Can I switch from haemodialysis to peritoneal dialysis, or vice versa?

It may be possible. If you feel that you need to switch, you should discuss it with your healthcare team.

I am worried that I may not be able to afford treatment.

Don't worry! There are societies such as the National Kidney Foundation (NKF) that offer financial assistance and subsidies to those who have difficulties affording dialysis.



UNDERSTANDING HAEMODIALYSIS

Haemodialysis remains a viable treatment option for many people with advanced chronic kidney disease.

Facts about haemodialysis

- It won't cure your kidney disease. However, it keeps you alive by performing the important functions that your kidneys used to do.
- First, your healthcare team will sew an artery to a vein, creating a **fistula** in your arm (called the **access arm**). This fistula allows needles to be inserted into the vein during haemodialysis.
- You can go for haemodialysis at haemodialysis centres, for about three times a week. Each session will last about three to four hours.

But what if the dialysis centre is too far from my home?

While there are a number of haemodialysis centres in the cities in Malaysia, you may experience difficulties finding one close to your home if you live in a more rural area. If traveling is a difficulty, it may be a good idea to discuss the peritoneal dialysis option with your healthcare team.



How can I make the most out of my dialysis sessions?

- Plan your schedule around your dialysis appointments, not the other way around. That way, there is no need to rush or ask your healthcare team to shorten the session duration (which isn't good for you).
- Eat in advance if you anticipate feeling hungry. You should eat at least one hour before a session and at least 30 minutes after.
- Bring along a coat or a thicker shirt if you find the haemodialysis centre too cold for your liking.

Fistula Care. To avoid infections and other problems, follow these tips:

- Wash your hands with soap and water before and after touching your fistula area. Clean the area with antibacterial soap before your haemodialysis session.
- Your healthcare provider will teach you how to check the pulse or thrill in your fistula access. Remember to do this every day.
- When you visit a clinic and you need to have your blood drawn or receive a drip, make sure it is not done on your access arm.
- Take care not to sleep with your weight on the access arm.
- Do not lift or carry more than 5 kg with your access arm. If you have a handbag, use your other arm to carry it.
- Also, avoid wearing watches, jewellery or tight sleeves on the access arm.
- Be on the alert for signs of infection such as redness, pus, bleeding and swelling. Inform your healthcare team immediately if you notice such signs.

A CLOSER LOOK AT PERITONEAL DIALYSIS

As you will be on your own or with your caregiver when it comes to peritoneal dialysis, it is important that you (and your caregiver) understand fully how to carry out the treatment procedure correctly. Therefore, always ask and seek clarification from your healthcare team if you have concerns.

There are two common types of peritoneal dialysis.

- **Continuous Ambulatory Peritoneal Dialysis (CAPD)** does not require the use of special machines. You can do it yourself, about four to five times a day (at home as well as at work or school – all you need is a clean space). You will attach your catheter to drain in a bag of dialysate and this fluid will dwell inside your abdomen for about four to five hours. While this is happening, you can go about doing other activities.
- **Continuous Cycling Peritoneal Dialysis (CCPD)** requires a special machine. While it works similarly to CAPD, it offers the added advantage of shorter indwelling time (about 90 minutes compared to four or five hours in CAPD) and it can be done throughout the night while you are asleep. As CCPD involves the use of a machine, though, cost is always one factor to consider when deciding between it and CAPD.

CATHETER CARE

Before you begin your peritoneal dialysis treatment, a tube-like structure called the Tenckhoff catheter will be surgically inserted into your abdominal area. Follow these tips to take good care of it.

- Keep the area clean and dry. If it gets wet, clean and dry both the catheter and the area around it right away.
- Wash your hands with soap and water before and after you touch the catheter.
- Avoid cutting, clamping or moving the catheter on your own.
- To avoid the catheter from getting stuck on your clothes, try taping it to your body.
- If you wish to swim, consult your healthcare team on the best way to prevent germs and contaminants from getting in through the catheter.
- Avoid lifting or moving heavy objects whenever possible. Try not to carry young children in your arms – they may accidentally kick at your catheter.
- Check the area around the catheter every day for signs of infection (swelling, redness, soreness, pus, bleeding, etc). You should see your healthcare team immediately if you notice these signs or if you experience pain in your belly, nausea or vomiting.

It is also important to know how to store your dialysis supplies properly and safely. Furthermore, have a list of numbers ready to call in case you have a medical emergency.

WHAT CAN I EAT WHILE I'M ON DIALYSIS?

"And I believe that the best buy in public health today must be a combination of regular physical exercise and a healthy diet." – Australian politician Julie Bishop

Proper nutrition is an essential part of your efforts to stay healthy despite having advanced CKD. Now that your kidney functions have been compromised, your nutrition goals are as follows:

- Obtain optimal energy and nutrients from your meals to stay healthy.
- Minimise disturbances related to electrolyte and mineral balance in your system.
- Manage and control your fluid intake.
- Delay complications related to dialysis as well as to manage other

co-existing chronic conditions you may have (diabetes, heart problems, etc).

There is no simple set of rules that can fit everyone with advanced CKD. Often, your dietitian will advise you on a suitable meal plan based on your weight and age, kidney condition, and other co-existing health problems you may have and other factors.

What this section hopes to achieve is to highlight a few important key points that you can use as reference as well as a starting point for further discussion with your dietitian.

SPECIAL NUTRITIONAL CONSIDERATIONS

This is only a general overview; you can consult your dietitian for more information.

PROTEIN

Protein is a nutrient that builds our muscles, repairs tissues and fights against infection. During the dialysis treatment, an average of 10 to 12 g of proteins is lost. Hence, you are encouraged to consume sufficient amounts of protein to maintain your overall health and wellbeing.

High quality protein food sources: meat, poultry (chicken, duck, etc), fish, eggs and soy products.



PHOSPHORUS

Phosphorus is a nutrient that supports calcium absorption in our body. However, dialysis may not be able to remove enough excess phosphorus from the blood, causing issues such as itchy skin and weak bones. Hence, you will likely be advised to limit your phosphorus intake.

High phosphorus food sources: dairy products, bone soup, internal organ, wholegrain, cocoa based drinks, dry beans and nuts.

Tip! Limit food that is rich in phosphorus. Take your phosphate binder with your meals and high phosphorus snacks to keep your phosphorus level within the recommended range.



POTASSIUM

Potassium is a nutrient that plays important roles in muscle contractions and heart health. However, with your condition, too much potassium can lead to heart problems. If your blood potassium is high, you may need to limit high potassium foods in your diet.

High potassium food sources: bananas, durians, jackfruits, tubers, coconut water, fruit juices.



FLUID

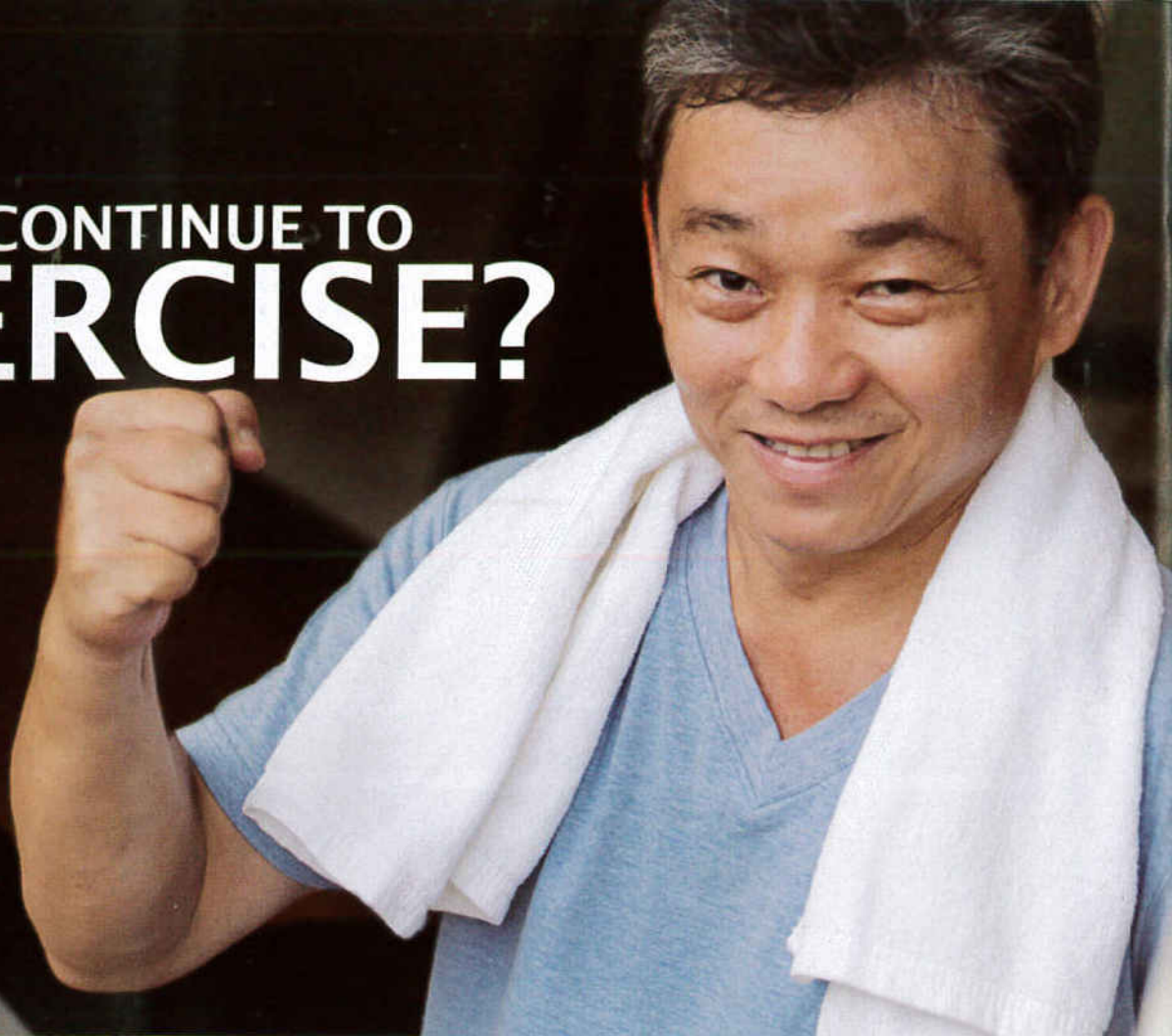
One of the main functions of the kidney is to remove excess water from the body. Due to kidney failure, it is important that you take some measures to manage your fluid intake.

What are fluid-rich foods? All kind of drinks, ice creams, porridge, ice cubes, soups, gravy and sauces.

Tips! Avoid salty food, as sodium can increase your thirst and subsequently your fluid consumption. Maintain a good blood sugar profile; you will feel more thirsty if your blood glucose level is high.



SHALL I CONTINUE TO EXERCISE?



Exercise is beneficial to people with chronic kidney disease, even those with advanced stages of the disease. Not only will regular exercise help strengthen the body, it also helps to maintain a healthy weight and reduce complications of diabetes, high blood pressure and other chronic health problems (which affect many people with kidney disease).

Furthermore, exercise can help lift the spirits and improve the mood.

What kind of exercises can I do?

Below is an example of an exercise plan. You should consult your healthcare team for the actual type and frequency of exercises that you can do, as they may vary depending on your condition.



Aerobic exercises

Taichi, brisk walking or cycling

3 times a week, 30 to 60 minutes each time

Strength-building exercises

Triceps extensions, forward lunges

2-3 times a week, 10 minutes each time. Rest on the day after.

WHAT ABOUT RENAL ANAEMIA?

The kidneys produce a hormone called erythropoietin (EPO), which plays a role in telling our bone marrow to produce more red blood cells when the need arises. When you have kidney disease, the production of EPO is affected. As a result, the body experiences a shortage of red blood cells – hence, anaemia.

Furthermore, if you undergo haemodialysis, you may also lose a little blood after each session, further increasing your risk of developing anaemia. Diet lacking in iron, vitamin B12 and folic acid as well as the presence of certain other health conditions may also increase this risk.

Heart problems

When your body receives less oxygen than normal, the heart will work harder to pump more oxygen-carrying blood. Eventually, the heart will experience problems such as enlarged heart muscles, irregular beats and even heart failure, stroke and death.

Do I have renal anaemia?

Symptoms of anaemia include

weakness and fatigue, headaches and dizziness, breathing difficulties and intolerance to cold. However, it is also possible that you may have anaemia and show no symptoms until the condition has reached an advanced, more serious stage. Therefore, keep up with your doctor appointments, so that he or she can do the necessary tests to check whether you have renal anaemia.

How is it treated?

Depending on your condition, the following may be prescribed:

- Increasing the amount of iron in your daily meals, usually via iron supplements taken orally (note: these are special supplements, not the ones that can be purchased from the pharmacy!) or via intravenous injection (drip).
- Medications called erythropoiesis stimulating agents (ESAs). ESAs contain substances that behave the same way as EPO, stimulating increased red blood cell production in the body.

CAN I GO BACK TO WORK?



If you wish to go back to work, share your intention with your healthcare team. They may have some recommendations on how you can do this without compromising your health. Here are some considerations you should keep in mind:

- If you have problems keeping to your dialysis schedule due to work, you should consider working part time or on a flexible schedule.
- You should avoid going back to physically demanding jobs.
- Your employer will no doubt have concerns about your ability to go back to work and how much your medical benefits will cost the company. You can arrange for your employer to have a discussion with your healthcare team, to clear these concerns.
- If you believe that you may be discriminated against at your workplace due to your condition, you can consult an employment lawyer or the Ministry of Human Resources (www.mohr.gov.my) for your next best course of action.

WHAT IF I NEED TO TRAVEL?



Yes, you can still travel, provided you make plans in advance.

- Consult your healthcare team on how to best go ahead without disrupting your treatment schedule.
- Let your family and healthcare team know of your travel plans.
- Make plans a few months in advance, so that you have enough time to go over your plan without overlooking anything important.
- If you are on haemodialysis, look up the nearest centres at your destination, their opening hours, contact numbers, the cost of seeking treatment there and how to make an appointment. Make sure you have these details with you when you arrive at your destination.
- If you're on peritoneal dialysis, pack all the supplies you will need for the entire trip as well as a few days more (just in case). In some countries, you can arrange in advance with the hotel to have peritoneal dialysis supplies delivered to your room.
- Bring enough of your medications for the entire trip as well as a few days more, to cover the possibilities of delays, missed flights, etc.
- You can discuss with your dietitian on the types of snacks you can pack along for those times when you need a quick bite.
- Keep a list of your prescriptions and medical supplies ready in your wallet or purse, in case your luggage goes missing when you arrive. Also, you can bring along copies of your medical records and doctor's prescriptions. If you are traveling with other people, make sure they know where you keep these lists and records. All this information will be useful should you experience a medical emergency during your trip.
- Also, if you are traveling for pleasure, plan your activities realistically. You should avoid overextending and exhausting yourself, so give yourself enough rest time amidst all your exciting adventures!

STAY POSITIVE

& AVOID BURN OUT

"I can't change the direction of the wind, but I can adjust my sails to always reach my destination." – actor and musician Jimmy Dean

Having to undergo dialysis can be a significant change to your lifestyle. You may feel hampered in your ability to go back to work, or to do the things you enjoy, such as traveling.

It can also leave an emotional impact. You may feel that dialysis is a sign of weakness or failure, or perhaps you fear that you may not have much time left in this world.

While this may seem like a cliché, you can eventually overcome these hurdles with a positive attitude as well as by seeking help and advice from your healthcare team, counsellors and even other people who are undergoing dialysis.

Let's join a support group

Being surrounded by and in close contact with fellow people on dialysis will make you feel less lonely. You and your fellow support groups can cheer and motivate one another when things

become challenging.

Feeling burned out?

Write it down. If you feel that things are too much for you, list down all the things that are bothering you. Rank them from most bothersome to least. This will help you get a clearer perspective of the types of challenges you are facing.

Share the list with your healthcare team. Beginning with the most bothersome item on the list, write down a few things you can do to overcome it. You and your healthcare team or support group can work out what these things are together.

Let's overcome the issue together.

Once you have a good idea of the things you can do to overcome the issue, set a realistic timeline to carry them out. At the end of the timeline, you can evaluate your progress. If you feel that you have resolved the issue to your satisfaction, then it's time to focus on the next item on your list.

If you or your loved one need advice and support, the National Kidney Foundation is here for you.



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Support groups are available, please contact us for more information.



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PHARMACEUTICALS

Renal Care Franchise



Restore
Your HOPE

Recharge
Your FAITH

Revive
Your Quality
of LIFE



Restore | Recharge | Revive