LENTEN SERIES 2018, REFLFECTION V - MANAGING A CHRONIC ILLNESS

I have been asked to close this Lenten series on wellness by focusing on how to cope and manage life after being diagnosed with a chronic illness.

Dr. Milbourn started the series on health and wellness by highlighting the definition of health - a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. Another salient point highlighted in the 1st reflection was that 'your health is your responsibility'. But responsibility needs to be coupled with individuals being equipped with the tools to handle the given responsibility – otherwise as we say in Jamaica, we would be giving you basket to carry water. So today, I hope to share with you on how to cope practically with major aspects of having a chronic illness.

But firstly, what is a chronic illness? A chronic illness is characterized by lasting three or more months, generally cannot be prevented by vaccines (because it is usually not infectious) and cannot be cured by medication, nor does it usually just go away. Chronic illnesses are also sometimes referred to as non-communicable diseases. Another feature of chronic illnesses is that they are more common as we age, but they can occur early in life. Most chronic illnesses arise as a result of modifiable and non-modifiable factors. In other words, there are factors that we have control over and others such has our hereditary factors that we aren't able to change. Health damaging behaviors - particularly tobacco use, lack of physical activity, and poor eating habits - are major modifiable contributors to the leading chronic diseases.

These illnesses can however, be controlled by lifestyle changes and medications thereby restoring quality and quantity of life. Locally in the media there has been a lot of attention being paid to non-communicable diseases by the Ministry of Health and other organizations. We see ads encouraging us to drink sufficient water instead of sweet drinks. That is a good example of an effective public education campaign demonstrating a simple way as to how a person's lifestyle can help to prevent or manage chronic illnesses such as diabetes and obesity.

Other common chronic illnesses include cardiovascular disease that can manifest as heart attack and stroke, hypertension, various autoimmune and forms of arthritis, seizures, chronic kidney disease, cancers, osteoporosis, <u>cataracts</u> and glaucoma.

Of course, being diagnosed with an incurable illness not only affects the physical body but also takes a toll on the person's mental, social and spiritual well-being. A chronic illness can be a life changing event. As a rheumatologist who cares for patients with arthritis and other pain syndromes, my patients are reminded daily when they can barely get out of bed due to their pain that they are no longer who they used to be.

The human response very often to hearing of the diagnosis of a chronic illness is fear and avoidance of accepting the diagnosis, sometimes even catastrophizing – thinking things are worse than they actually are. Jamaican patients tell me daily 'mi not claiming this doc', 'stop wishing bad tings on me' or 'in the name of Jesus, I rebuke this illness'. These reactions are to some extent understandable but at the same time are damaging behaviours which lead to lack of taking action, feelings of helplessness and hopelessness, depression and poor outcomes. You must take action. Prayer helps with giving hope, comfort and strength but is usually not sufficient by itself to get rid of disease, albeit divine intervention. How you cope will partly determine your outcome.

Apart from fear, other key determinants that have been identified to influence whether people have healthy or unhealthy endpoints after developing a chronic illness include:

- <u>Social support</u> networks
- Education and literacy
- Income and <u>social status</u>
- <u>Social</u> and <u>Physical environments</u>
- Health care services
- Personal health practices and coping skills
- Biology and genetics
- Gender
- <u>Culture</u> and spiritual beliefs
- Employment/working conditions

Healthy <u>child development</u>

With so many factors at play, you must be asking yourself, how do you take control of a situation such as having a chronic illness.

So we are going to go through a few steps:

ACCEPT YOUR NEW NORMAL – as difficult as it may be and it may take time. As a believer and a follower of Christ, remember you are not alone. 1 Peter 5:7 reminds us 'Cast all your anxiety on him because he cares for you'.

YOU ARE ABLE – Phil 4:13 I can do all things through him who strengthens. You are no less able than anyone else to contribute to your wellness and health. You are not any less deserving than others to have good quality of life and wholesomeness. It will take good practices and attitudes to achieve the best health circumstance possible for you, but it is possible. Some persons will have additional limitations and challenges. For example, if your pocket is weak, you will have to push harder but make sure you use every option and explore every avenue possible to gain the best.

YOUR HEALTH IS UNIQUE and not quite the same as your neighbours. It is good to share with others and get suggestions but always check with the experts if this fits in with your needs.

YOU ARE YOUR BEST ADVOCATE for your health and the health of your loved ones. You need to create partnerships with others: your physicians, nurses, pharmacists, nutritionist, physiotherapist, etc. Each person has specialized skills and you need to tap into them. Your doctor is not necessary your best resource for everything. Also, you need to let persons know when there are concerns and also when you need help. Don't assume they know. If you don't understand the condition, you are having difficulty with a new diet or you can't afford a medication, then say something. There is no shame. Help may be available but if others don't know, they will not assist you. For example, there may be support groups available, samples the doctor can give, direction to the Ministry of Health for financial assistance.

EDUCATION IS ONE OF YOUR BEST TOOLS – SELF EMPOWERMENT AND MANAGEMENT SKILLS are invaluable. The more you know, the more you can grow in your health journey. Your will be able to know what is helpful and what is

harmful. Education will help you to acquire self-management skills which have been shown to improve patient outcomes. Ultimately, your health practitioners are there to share knowledge as to the pros and cons of your health situation and recommend what they think is best but you ultimately make the choices that impact your health the greatest. Always be cognizant that not all information in the public domain is correct or that you may need help with the interpretation of medical information.

WHAT CAN YOU ACTIVELY DO TO HELP YOURSELF & MAKE THE BEST OF LIMITED RESOURCES

Maintain compliance with medication and other regimes eg.diet, exercise

Manage your medications – know the drugs you take and what they are used to treat. Do things to help you day to day to remember – place medicine bottles by toothbrush or where you sit to eat your meals, place alarms on your phone, etc.

Address the side effects of the medications (eg weight gain). Don't just stop the medicine - inform the prescribing physician – there may be an alternative or another way to combat the unwanted effects of the therapy

Ensure needed lifestyle adjustments are made – DIET, EXERCISE, REST, STRESS REDUCTION, DON'T SMOKE, LIMIT ALCOHOL and CAFFEINE

Keep your appointments and do requested tests - monitoring is used to ensure your health is heading and staying in the right direction

How can you cut costs – NHF/JADEP cards, use Drug Serv/ look for discounts, go to distributor for the drug, ask lab about available discounts (shop around).

Support groups – he who feels it knows it, may be able to tangible assist as well as help with education. For example, The Cancer Society of Jamaica, The Lupus Foundation of Jamaica

Extended Family – make it a family affair including work, church, community

Discuss appropriate ways to have access to your doctor and allied workers and their advice in between visits eg. office hours, phone, email so that issues are not left hanging for months.

Beware of depression and anxiety that may be associated with your illness and address early. Some chronic illness are associated with depression not because the person is weak but because the mechanism of the illness results in depression. Depression is not an example of being a failure as Christian. If your psychological health is not dealt with, your physical health usually remains subpar. For many of us as Christians, our wellbeing is largely directed by our spirituality.

THE SPIRITUAL ROLE

Spiritual beliefs may both positively and negatively affect coping. Make sure you use your religious beliefs to the benefit of your health, not spending extended time on why God has allowed this to happen. Let your beliefs be the rock and comfort it is meant to be but not false hope for impractical expectations. God gives power to cope to those who are tired and worn out.

1 Tim 4: 7-9 highlights the need for us to spend time training ourselves in spiritual fitness as it promises a reward in both this life and the next

Prov 17:22 helps us to remember that a cheerful heart is a good medicine, but a downcast spirit makes one sick (dries up the bones)

REWARD YOURSELF! Part of fostering good psychological health is: when you do good and achieve goals, do something for you. Leave room for small failures in your health journey as you are human but try to correct as soon as you can.

YOUR HEALTH IS YOUR RESPONSIBILITY It's a journey that you will walk with throughout life. There will be delays and bumps along the way, for some the road may be more winding than for others. You are not meant to walk it alone. May your desired destination of wellness be reached as you take charge of one of the most important aspects of your life.