A Guide to Type 1 Diabetes Management, Technology, and Everything Else You Need to Know

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By

May Ng

Cambridge Scholars Publishing

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This book is dedicated to my parents for giving me the foundations of life and the unconditional love to be who I am.

To my children Brendan, Darren and Corinne- you are my reason for being. To my husband Eugene- I look forward to getting old together.

Essentially, I would never have written this book without the conversations, wisdom and encouragement of patients and families I have worked with over the past 30 years. You have inspired me to bring the minefield of old and new information related to Type 1 diabetes management, technology and everything else you need to know into this book. This book is also dedicated to you, the people and families living with Type 1 diabetes.

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BOOK ENDORSEMENTS

"This is a great introduction to living with Type 1 diabetes both for healthcare professionals and people living with the condition. It covers all aspects of day-to-day management, including how to get the best out of the latest technology that's available. An invaluable resource that is highly recommended."
—Chris Askew OBE, Chief Executive of Diabetes UK

"This is a wonderful book! It is clear and informative. As a resource, it is essential reading for anyone living with or caring for someone with Type 1 diabetes. It unpacks the medical facts of Type 1, key information needed to self-manage the condition and the rapid advances in treatment technologies now increasingly available. Professor Ng is one of the UK's leading clinicians on Type 1 diabetes and I would highly recommend this book to anyone living with or caring for someone with the condition."
—Karen Addington, JDRF Chief Executive UK

"In her characteristic easy-to-read manner, Professor Ng's third book brings to life the A to Z of Type 1 diabetes care. It comprehensively covers the entire range of information on Type 1 diabetes, from the most basic to the most up to date, from theoretical basis to practical tips, from medical to psychosocial aspects of living with the condition, and from using different types of insulin to new technologies such as glucose sensors, insulin pumps and automated insulin delivery systems."
—Professor Ngee Lek, Senior Consultant Endocrinologist, Singapore.

"In this book Prof Ng has managed to synthesise a vast array of information on managing and living with T1D. It is presented in a format that is accessible to professionals, patients and carers. This is no mean feat given the complexities of diabetes management. Of note, she has considered the integration of diabetes into real life, including the technological agenda, not leaving behind emotional impacts. I can certainly highly recommend this book to anyone who has anything to do with T1D."
—Professor Helen Cooper, Emeritus Professor of Diabetes, United Kingdom years old, and living with Type 1 diabetes for 59 years.

"Professor Ng's book is timely and necessary to provide clear and practical steps to support anyone with Type 1 diabetes. It really is a book about everything you need to know on Type 1 diabetes management!"
—Mrs Ross Taylor, parent of Amy, age 6 with Type 1 diabetes.

"Professor May Ng is one of the world's experts in treatment and care for patients with Type 1 Diabetes, working daily with patients in the UK National Health Service. This book is a comprehensive reference guide - a 'one stop shop'. It explains everything clearly in an easy-to-read, useful detail. We can often be deluged by information from a mix of good and less good sources, so it is enormously helpful to have this authoritative guide. There are also many valuable links to other sources of information. I could not recommend it more strongly to anyone with or caring for someone with Type 1 Diabetes, or to those working in the field."
—Richard Toomey CBE, Chair of Trustees, Action4Diabetes

"This is the book to have with you if you have anything to do with Type 1 diabetes. A much needed, timely resource available at your fingertips, to help guide you through the ever-changing management of Type 1 diabetes with cutting edge technology. Once again, Professor Ng has provided a practical, jargon-free, essential guide for patients, their carers and her healthcare professional colleagues."
—Hannah Kyprios, specialist diabetes dietitian, United Kingdom.

"Professor May Ng is an award-winning specialist and an international leader in her field, with an impressive five degrees under her belt. This book is her third book following the success of '*A Journey with Brendan'* and *'Me and My Hormones-What Can Go Wrong*'. Readers will find a wealth of essential information in this book from pathophysiology of Type 1 diabetes, new diabetes technology and how to optimise day-to-day management. It should be on the shelves of anyone with Type 1 diabetes."
—Michelle Quinn, diabetes educator and patient advocate, United Kingdom.

"Not only does Professor Ng understand the biological and medical science behind new treatments and technology to help Type 1 diabetes management, but she also understands and empathises with the human side of diabetes management. This book is bang up to date, and relevant to all healthcare professionals, those who care for people with Type 1 and those who live with this complex condition. I thoroughly endorse May Ng's book as a unique and valuable T1 resource."
—Jerry Gore, age 60 years with Type 1 diabetes, International Diabetes Federation Global Ambassador, Co-Founder Action4Diabetes

"Prof Ng's book does exactly what it says on the tin! She writes comprehensively about first principles of diabetes from physiology, diagnosis and then extensively through all treatment

options. She weaves 'Language Matters' throughout and actively demonstrates the importance of supportive and empathic care for people with diabetes. This is an excellent resource for health professionals, parents and carers and anyone who has an interest in Type 1 diabetes."
—Maria Leveridge, specialist paediatric diabetes dietitian, United Kingdom.

"This book covers absolutely everything you need to know about living with or supporting someone who has Type 1 diabetes and helps make sense of complex and stressful information in a way that is kind and easy to read. A must-read for anyone with an interest in diabetes!"
—Dr Rose Stewart, Consultant Clinical Psychologist, Chair of Diabetes Psychology Network, United Kingdom.

"With technology moving so quickly, it can be difficult to keep up and have all the information required in one place. This book covers all aspects of Type 1 from basics to in-depth topics and leaves no stone un-turned. The valuable information is super easy to read thanks to Prof May Ng's amazing way with words. If you are working in diabetes or living with diabetes, this book is a must have."
—Sam Barnard, diabetes specialist nurse and living with Type 1 diabetes for 20 years, United Kingdom.

"Prof Ng's third book is a fantastic resource for anyone who wants to get to grips with their condition. Written in a clear and concise manner, it is almost as if I can hear her talking to me and explaining all the different aspects in her easy-going manner. I am certain this will be a really valuable guide for people with diabetes, their carers and all healthcare professionals."
—Professor Pratik Choudhary, Professor of Diabetes, United Kingdom.

"This fantastic book from Prof Ng talks you through day-to-day life of ups and downs and all things Type 1 diabetes. It is a fantastic resource for diabetes specialists as well as people living with Type 1 diabetes in gaining a diverse understanding of this complex condition."
—Diabetes Specialist Nurse Forum, United Kingdom

"Congratulation to Prof May Ng for this outstanding offering to the Type 1 Diabetes community. Each chapter is carefully crafted with clinical expertise and inside insights into the life of someone living with Type1 resource. The plethora of topics and the depth of each covers every aspect of management in a clear and crisp way. It is robust and yet easy-to-understand and I wish I had this type of handbook when I was growing up with Type1 resource."
—Jazz Sethi, Founder/ Director of The Diabesties Foundation, India

"With the rapid advances in diabetes technology, there is an urgent need for an up to date manual to navigate one's way around therapeutic developments in this area. Professor Ng has managed to condense a vast array of complex and up to date information into a highly readable and accessible book, full of practical advice. This is not a book to sit on a shelf, but to have on one's desktop and in the clinic. I shall look forward to using this in my daily practice."
—Professor Timothy Barrett, Professor of Paediatrics, United Kingdom

FOREWORD

Professor May Ng is a consultant endocrinologist with decades of experience looking after children and young adults with diabetes. She has three Masters degrees in endocrinology (MSc), law (LLM), business and finance (MBA), and a PhD in endocrinology. A remarkable five academic degrees under her belt, she has published more than 150 academic research papers and served in many national and international roles developing policies and guidelines to improve the health outcomes of people with diabetes.

Type 1 diabetes is due to an autoimmune process that destroys beta cells in the pancreatic islets, resulting in insulin deficiency. Insulin replacement therapy remains the gold standard. Despite advances in insulin preparations, insulin delivery and glucose monitoring, diabetes outcomes globally are suboptimal, leading to long term diabetes-related complications. In addition, affordable insulin access remains a challenge for many people around the world.

Insulin was discovered in 1921 by Frederick Banting and Charles Best, who successfully isolated insulin from dogs. In 1922, 14-year old Leonard Thompson became the first person to receive an insulin injection as treatment for his Type 1 diabetes. A 100 years later, 2021 marks the centenary of insulin discovery and insulin remains the only life-saving treatment for Type 1 diabetes. Scientific advances have moved the diabetes field forward since Leonard Thompson first received insulin a century ago. Type 1 diabetes care is evolving at pace and new approaches are now emerging which offer people with Type 1 diabetes a different trajectory, such as newer insulins and the advent of diabetes

technology in the last decade.

One of the biggest challenges for any healthcare system is how to support people with Type 1 diabetes, a condition that can be all-consuming and relies heavily on self-management. Managing Type 1 diabetes is based on three basic principles -self-management, peer support and access to trained healthcare professionals. A person with Type 1 diabetes spends around 0.02% of their year in direct contact with the NHS for their diabetes management, if we assume four visits of 30 minutes each, leaving 99.98% of their time having to deal with the challenges of the disease. Self-management can be tiring and tough on mental health, and people rely on good consistent information and education provided by their healthcare providers from diagnosis.

Professor Ng has now written a book that should be on the bookshelves of anyone with Type 1 diabetes and any healthcare professional looking after patients with diabetes. May Ng's style is engaging, easy-to-read and comprehensive. She has not missed a beat on this complex topic. May Ng explains the complex science of diabetes in a clear approach based on the most up-to-date research evidence, her medical knowledge and her experience.

She introduces the reader to key pathophysiology of various types of diabetes and the different forms of insulin and insulin regimens. She provides up-to-date information on new insulins, insulin pumps, closed-loop systems, continuous glucose monitoring systems, and how to interpret blood glucose data from downloads. She also provides practical daily advice on how to self-manage diabetes to maintain a healthy lifestyle, from meal-planning, exercise adjustments, managing high or low blood glucose, avoidance of diabetic ketoacidosis, travelling with diabetes and the importance of diabetes annual health checks. Topics on COVID-19, transition, mental health and solution-focused approaches are particularly useful to support and

empower the person with diabetes to achieve the complex juggling act required to manage their condition.

In the later chapters, May Ng describes the importance of language matters and pleads to healthcare professionals to make a deliberate effort to choose appropriate language during consultations. Healthcare professionals can build robust and sustainable working relationships with their patients by a determined effort to mind our language, choosing each and every word we use. The final chapter has many useful links to resources that healthcare professionals and people with Type 1 diabetes can access freely. Through what often feels like a complex and disorientating maze for anyone living with Type 1 diabetes, this book provides a blueprint and a guide to educating and self-managing Type 1 diabetes without lacking in detail or depth.

This is a book which blends traditional science with modern adaptations and up-to-date evidence-based research in an engaging, easy-to-read style that I found most useful as well as enjoyable.

Professor May Ng has written an all-in-one book aimed at healthcare professionals, trainees, nurses, medical students, carers, parents and people with Type 1 diabetes. This book will become an invaluable resource and essential reading for many, and I would highly recommend it.

—Professor Partha Kar OBE.
Consultant Endocrinologist and National Specialty Advisor for Diabetes NHS England, United Kingdom

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INTRODUCTION

Type 1 diabetes care is changing rapidly. In just over a decade, diabetes technology has become more widely available and is now part of routine self-management in most parts of the world.

I have been looking after people with Type 1 diabetes for more than 30 years, and this book is about translating theory into clinical practice with an aim to help those with Type 1 diabetes to self-manage and live well. This book is also for parents, carers, partners, doctors, nurses and students to increase their understanding of Type 1 diabetes and the emerging technology that has evolved in the past decades. The healthcare professional-patient relationship is one of collaboration, and recognising that the person living with diabetes is the expert in their condition. Success comes from empowering and educating the person to live well with their diabetes.

This book is not meant to be an exhaustive review but is written for anyone who wishes to gain a practical understanding of Type 1 diabetes. It can be read from cover to cover, or it can be used as a guide and reference of specific topics that arise over the years. Many of my colleagues, students, people with Type 1 diabetes and their carers have often asked for an easy-to-read, bite-sized source for understanding this complex condition. I became convinced this book was needed.

The landscape in the last two decades when it comes to managing Type 1 diabetes has changed dramatically. There is increasing awareness of diabetes as a major public health issue and therefore

increase in research into prevention, complications, education and diabetes technology. The chapters on diabetes technology cover topics such as difference in insulin pumps, newer insulin, continuous glucose monitoring systems, hybrid closed loops and understanding downloads of blood glucose and insulin pump data are of the most up-to-date at the time of writing. This book fills a gap in the current market of diabetes books and reflects the ever-changing face of Type 1 diabetes management.

The chapters on COVID-19 are based on the most recent evidence published related to the risks of diabetes and COVID-19 infection. The chapters on 'language matters' and living well with solution-focused approaches are especially important whether you are a parent, carer or a healthcare professional. It is important to remember that language has a significant impact on increasing motivation and affecting behaviours.

Poor use of language can be stigmatising, hurtful and undermining of self-management. Language used in a positive, kind, understanding and emphatic manner can lower anxiety, build confidence and enhance self-management. Remember that supporting an individual's mental health and well-being is just as important as ensuring they take their medications or check their blood glucose.

The information provided is true to the best of my knowledge as a practising specialist in diabetes and who has held national and international roles in developing international diabetes guidelines and policies. It is not intended to replace or countermand any advice given to you by your own physician or diabetes team. Any decisions made regarding your diabetes care should always be collaborative and discussed between you and your healthcare provider.

I am very grateful for all the endorsements from patients, parents, colleagues, Diabetes UK, JDRF and Action4diabetes, and many

who have given me the feedback from its initial draft to further improve on its content.

Finally, when my oldest son was given a diagnosis of non-verbal autism, my second son was born deaf with congenital sensorineural deafness and my daughter was born premature, my default coping mechanism was always to research and learn more about how I could support them. We are never too old to keep educating ourselves. Be brave to venture and learn. I leave you with one of my favourite quotes and philosophy in life by Lucius Annaeus Seneca,

> "It is not because things are difficult that we dare not venture. It is because we dare not venture that they are difficult."

—Professor May Ng

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Honorary Professor and Consultant Paediatric Endocrinologist, United Kingdom

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DIABETES

The word 'diabetes' is derived from the Greek word meaning 'a siphon' because people with diabetes pass water like a siphon. Note that while both diabetes mellitus and diabetes insipidus share the same word 'diabetes', they are both very different conditions that have similar characteristics of excessive urination (also called polyuria). Diabetes on its own usually refers to diabetes mellitus, with the word 'mellitus' deriving from Latin meaning sweet.

Diabetes mellitus is a condition that causes abnormally high levels of blood sugar (referred to also as blood glucose). When we eat or drink, the carbohydrates are broken down in the body into glucose and other nutrients. This is then absorbed through the gut intestinal walls into our bloodstream. Glucose is the main fuel that is used by the cells in the body for energy.

Insulin is an important hormone made by beta cells from the part of the pancreas called Islets of Langerhans. Islets of Langerhans make up only an estimated 1% to 2% of the total pancreas. Insulin regulates how much glucose is produced by the liver and lowers blood glucose levels. While there are several hormones in the body that can raise blood glucose levels, only insulin hormone lowers blood glucose levels. To be healthy, blood glucose levels should not go too high or too low. When we eat and drink, our blood glucose levels will rise, and this causes the pancreas to produce insulin. Insulin acts as the key that allows the glucose into the cells to lower blood glucose levels.

In people with diabetes, the body either fails to produce any insulin, has insufficient insulin, or the body fails to respond to the amount of insulin that is produced. There are different types of diabetes that will be discussed in this chapter.

Diagnostic criteria

The World Health Organization (WHO) diagnostic criteria for diabetes is a fasting blood glucose greater than or equal to 7.0 mmol/L (126 mg/dL) or a random blood glucose greater than or equal to 11.1 mmol/L (200mg/dL).

A glucose tolerance test can be used to measure the body's response to sugar and involves having a fasting blood glucose test and a 2-hour blood glucose test after 75 grams of glucose is taken by mouth. A glucose tolerance test can be used to determine glucose tolerance in individuals who may have impaired glucose tolerance, suspected gestational diabetes during pregnancy or those who have a fasting blood glucose between 6.1 mmol/l-6.9 mmol/L (110-125 mg/dL).

Type 1 diabetes

Type 1 diabetes is thought to be caused by a combination of genetic susceptibility as well as unknown environmental factors such as a viral infection. Several pancreatic islet autoantibodies have been associated with the pathogenesis of Type 1 diabetes with varying sensitivities. However, the majority of people who are diagnosed with Type 1 diabetes do not have a family history of diabetes.

Type 1 diabetes is the most common type of diabetes in children and affects around 1 in every 1000 children. There has been a steady increase in the diagnosis of Type 1 diabetes in children under 5 years of age in the past few years. Globally, diabetes was the direct cause of 1.5 million deaths, however, there is no

epidemiologically accurate information on the prevalence or incidence of Type 1 diabetes worldwide. Based on research data extracted between 1990 and 2019, the incidence of Type 1 diabetes in continental subgroups (Asia, Africa, Europe, and America) was estimated at 15 per 100,000, 8 per 100,000, 15 per 100,000 and 20 per 100,000 respectively. In the United Kingdom, in 2021, there are 400,000 people currently living with Type 1 diabetes, with 30,000 children and young people up to the age of 18 with Type 1 diabetes. In the USA, there are 1.6 million Americans living with Type 1 diabetes, including 200,000 youths less than 20 years old. Type 1 diabetes can develop at any age but usually appears before the age of 40 years. Based on the International Diabetes Federation (IDF) Diabetes Atlas 9th edition, there are an estimated 600,900 children under 15 years living with Type 1 diabetes worldwide, with this figure almost doubling to 1,110,100 for under 20 years of age.

Type 1 diabetes is an autoimmune disease whereby the body's own immune system attacks and destroys healthy beta cells in the body by mistake. This results in a lack of insulin. Type 1 diabetes usually develops over a few weeks, and symptoms are increased thirst, tiredness, going to the toilet frequently to pass urine, weight loss, regular episodes of thrush and blurred vision. Without insulin, people with untreated or poorly managed Type 1 diabetes will lose weight because fat tissue and protein, mainly from muscle, are broken down as an alternative energy source because glucose is unable to enter the cells. Breakdown products such as fatty acids and glycerol are broken down from fat and are used by the body as a reserve for glucose supply. Fatty acids are also transformed into ketones in the liver and glycerol changes to new glucose. These reactions can also occur as 'starvation ketones' if one is fasting or too ill to eat, and both starvation ketones and diabetes ketones are similar chemically.

In Type 1 diabetes, as more and more ketones are being produced due to lack of insulin, it makes the blood acidic and causes diabetic ketoacidosis. This can lead to vomiting, abdominal pain, rapid breathing, dehydration and drowsiness. If insulin is not given, diabetic ketoacidosis coma can develop and could prove to be fatal.

A blood test will show high blood glucose levels and a urine test will show the presence of glucose in the urine. If blood glucose levels are high, the body loses water by causing more urine to be passed, and dehydration can occur. Ketones can be measured in the blood or the urine in the doctor's surgery or by the bedside using a hand-held monitor.

Maturity-Onset Diabetes of the Young

Maturity-Onset Diabetes of the Young, or also known as MODY, affects around 1% to 2% of people with diabetes. A number of different genetic mutations have been shown to cause MODY. MODY is often treated with oral medications or insulin therapy. However, some forms of MODY may not require any treatment. The specific treatment may vary depending on what genetic mutation caused the condition.

HNF1-alpha is a genetic mutation that comprises 70% of MODY cases and is usually diagnosed in adolescence and early 20s. It limits the amount of insulin made by the pancreas, and treatment is by oral medication tablets called sulfonylureas (an oral medication usually used for Type 2 diabetes).

HNF4-alpha is a genetic mutation and is also generally treated with sulphonylurea medications but may require insulin as the disease progresses.

HNF1-beta is a genetic mutation that is associated with the development of renal cysts (cysts of the kidneys), uterine

abnormalities, gout and diabetes. Often the renal cysts can be detected in the womb before a baby is born. Insulin therapy is usually required.

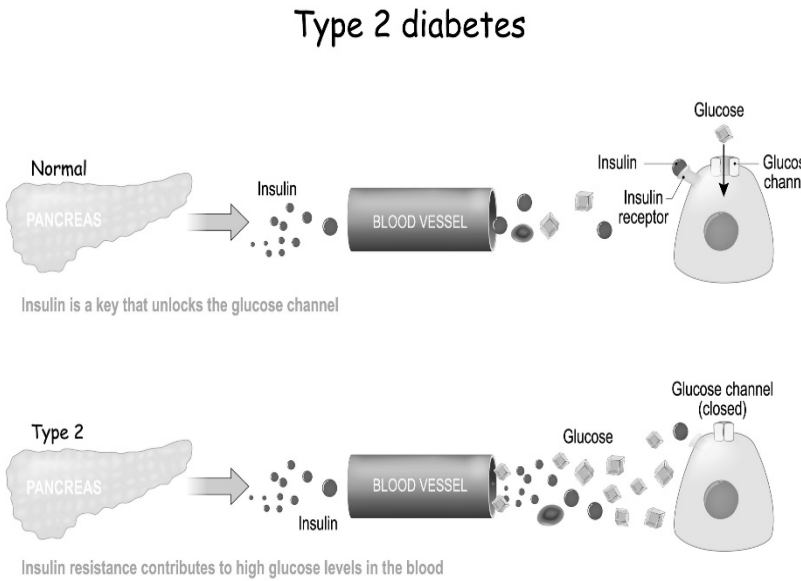
Glucokinase is a genetic mutation that results in the body having slightly higher blood glucose levels, and there is no treatment required for this condition.

Type 2 Diabetes

In Type 2 diabetes, the beta cells are still able to produce insulin, but insulin is not produced enough or is no longer used effectively by the other cells in the body, resulting in the body's sensitivity to insulin being reduced. Fat and muscle cells become 'insulin resistant' and initially, the body can compensate for this by increasing its production of insulin. However, as the disease progresses over the long term, gradual failure of insulin production may occur which leads to insulin deficiency.

Type 2 diabetes is associated with other metabolic abnormalities such as dyslipidaemia, hypertension, polycystic ovary syndrome and fatty liver disease. Unlike Type 1 diabetes, there is no identified autoimmune process in Type 2 diabetes.

Type 2 diabetes usually occurs in adults, but we are seeing an increasing incidence of children diagnosed with Type 2 diabetes worldwide. There is an estimated 4.7 million people in the UK who have a diagnosis of diabetes, of whom 90% have Type 2 diabetes. The number has more than doubled in the past 20 years and Diabetes UK predicts that by 2030 this will exceed 5.5 million. Type 2 diabetes is a growing health problem globally affecting over 400 million people worldwide. There are other factors such as genetics that also play a significant role in Type 2 diabetes. For example, having a parent with Type 2 diabetes significantly increases the risk of developing Type 2 diabetes.



Being overweight and over-eating is also linked to an increased risk of developing Type 2 diabetes, which is a vastly different condition to Type 1 diabetes. The two conditions can be often be confused amongst family and friends. However, the exact cause of Type 2 diabetes is unknown. Obesity is certainly not the only risk factor as many children and adults who are overweight do not all develop diabetes, but being overweight is associated with the risk of development of Type 2 diabetes. Overweight children, young people and adults have an increased risk of developing insulin resistance because the body struggles to regulate insulin.

At a societal level, reducing childhood obesity will reduce the risk of developing Type 2 diabetes by encouraging and practising healthy eating habits, eating well-balanced meals while also having regular exercise and being physically active. These will help maintain a healthy weight and reduce the risk of Type 2 diabetes. Social deprivation and low socioeconomic status are also risk

factors for obesity and Type 2 diabetes. Families and people from more deprived areas face a greater challenge in making healthier lifestyles.

Type 2 diabetes is usually managed initially by adopting a healthy lifestyle, diet and exercise in order to achieve their target blood glucose levels. Some people may also need diabetes medications or insulin therapy. The decision about which diabetes medications depends on many factors and any other health problems that warrant a discussion with your doctor.

Neonatal Diabetes

Neonatal diabetes mellitus is a rare form of diabetes characterised by high blood glucose levels occurring in the first six months of life. We now know of at least 23 different genetic causes of neonatal diabetes. Neonatal diabetes mellitus affects approximately one in 300,000 to 400,000 babies and can present as poor feeding, failure to thrive and, in some cases, severe dehydration leading to diabetic ketoacidosis. Treatment varies according to the underlying causative gene. In around 50% of neonatal diabetes infants, treatment with oral sulphonylureas can effectively manage the blood glucose levels to achieve normal targets and subcutaneous insulin therapy is usually not required.

Neonatal diabetes may be transient (with a resolution by 12 months of age) or permanent. More than 90% of cases of permanent neonatal diabetes mellitus are caused by a KCNJ11 or ABCC8 genetic change. This affects the link between sensing of blood glucose levels and the release of insulin from the pancreatic beta-cells.

Cystic Fibrosis Related Diabetes

Cystic fibrosis is an inherited genetic condition due to mutation in the cystic fibrosis transmembrane conductance regulator