

## Recommendation to readers by Professor David Smith

Dr Joseph Chandy, a practicing doctor for almost 50 years, has written a fascinating and important book. Some 20 years after starting to practice, Dr Chandy came across a patient with vitamin B12 deficiency who presented with neurological symptoms, but without the characteristic changes in blood cells. In the subsequent 30 years, he dedicated himself in General Practice to identifying and treating patients who had insufficiency of B12. The book vividly describes this very human story and the challenges he faced from the authorities who were reluctant to admit that he was making the correct diagnoses. The authorities behaved very badly in prioritising the 'rule book' over the clinical symptoms. The book shines throughout with Dr Chandy's devotion to the well-being of the patient and it should be read by all GPs, in training and those with experience. Medical scientists should also read the book since Dr Chandy ranges across several areas of medicine where much more research is needed. The book is very readable and full of helpful practical information. If the regulatory authorities read the book, it could lead to an improvement in an unsatisfactory aspect of the current practice of medicine.

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## Dedication

God's will be done. Shortly after I started working in the NHS, I was responsible for a programme to bring quality improvement to many places, including a small GP practice in a little known part of north-east England, in Horden. There I made the most unlikely encounter, with a GP who had held firm to his belief in the importance of vitamin B12, in spite of numerous attempts to silence him – legends that would one day be put in a book.

I was intrigued. This doctor said that modern medicine isn't always for good, that we're forgetting some of the old-fashioned truths, and – most radical of all – that a simple nutritional deficiency could be responsible for a whole range of illnesses and syndromes that had elaborate descriptions and were named after this famous doctor or that famous researcher.

I already knew that many of the “new ideas” being promoted in the NHS, most of the good ones anyway, were recycled from 70 years of NHS history, and Dr Chandy certainly needed help. At first my job was to do the analysis and reporting for the Primary Care Trust (PCT), which showed that Dr Chandy and the Shinwell Medical Practice were complying with the restrictions imposed on his Practice. However, my closeness to the figures showed me that B12 deficiency is a significant reality, and that B12-replacement therapy (by oral tablets and by injections) did appear to remit the symptoms in many hundreds of patients, far more than could be explained simply by a placebo effect, and I was hooked.

Dr Chandy was destined to remind us, all of us, of the beautiful simplicity of God's world and the paths He has chosen for each of us. My part was to join this journey 25 years after it was started; to bring rigour and analysis to the treatment of patient after patient; and ultimately to write down Dr Chandy's vast knowledge and compare it with the published scientific and medical literature. I don't think I chose to be a part: it just came about.

I commend this book as probably the most definitive guide to B12 deficiency. It is based on nearly 40 years of personal observations in patients whose health Dr Chandy has been responsible for, not on an episodic basis, but for their whole lives from youth through adulthood and into old age.

**Hugo Minney, Ph.D.**

## Preface

In 1981, I encountered my first case of vitamin B12 deficiency without macrocytosis. This dramatic discovery led me to a persistent and lifelong interest in the role played by this essential micronutrient in the human body. Over the next three decades, I discovered that B12 deficiency is far more prevalent in the population than the current paradigm suggests. As I delved deeper into the subject and the story unfolded, I found that many conditions not recognised as B12 deficiency nevertheless responded well to B12 supplementation, to the extent of complete remission from symptoms of many diseases considered incurable.

The journey has not been easy. I encountered strong resistance and inflexible views about how treatments in medicine should be made. It is not easy to overturn entrenched opinion but I could not deny the overwhelming evidence before my eyes: vitamin B12 therapy can cure many conditions and saves lives! Despite many setbacks in getting my discoveries acknowledged, I have drawn encouragement from the appreciation of my patients, the support of some receptive members of the medical profession in both Britain and India, and the many enquiries which have poured in to me from sufferers and doctors all over the world.

The effects of untreated B12 deficiency are devastating and can cause untold human suffering. I came to the medical profession out of a commitment to help my fellow human beings. This book is written to alleviate that suffering by sharing the extensive experience of B12 deficiency that I acquired over many years as a General Practitioner in the north-east of England. It is my fervent wish that this knowledge will help to guide future treatment and research in this crucial area, and help to eradicate the widespread ignorance of the condition and its frequent misdiagnosis.

The investigation of vitamin B12 deficiency has been not only a fulfilling clinical experience but also an intense spiritual journey.

I have the greatest respect for all faiths but in my personal life I have always felt guided, sustained and strengthened by my own particular Christian faith. Without this guidance, I would not have had the clarity of vision to recognise the symptoms of vitamin B12 deficiency, nor the courage to adhere to my convictions in the face of opposition. For this reason, I have thought it appropriate to include in this book references to events in my life of particular spiritual significance to me, and quotations from the Bible and other Christian texts which have inspired me.

**Dr Joseph Chandy (Kayalackakom),**

**Horden, County Durham, United Kingdom, 1 May 2019**

## Acknowledgements

In researching and writing this book I am deeply indebted to my family, GP and nurse colleagues and all the staff and patients of Shinwell Medical Practice, Horden, County Durham, UK. A very special thankyou goes to Hugo Minney for his invaluable contribution to the B12 cause since he joined the Shinwell Medical team.

I would like particularly to thank the late Ernie Bostwick and Betty his dear wife, the late Colin and Norma Reynolds, Susan Peacock, Ann Peel, Margaret Greenhalgh and Leanne Walker (née Chandy) for their various devoted contributions to my work and this book.

I also gratefully acknowledge the support and interest of all those in all walks of life who have supported my work by responding helpfully to submissions, inviting me to speak at conferences and providing evidence by testimony. I have greatly appreciated their encouragement. In particular, I wish to thank Professor A. David Smith, Emeritus Professor of Pharmacology, University of Oxford, for allowing me to reproduce (in Chapter 2) his letter of 29 November 2013 supporting my work, the Executive Chairman of the Pernicious Anaemia Society Martyn Hooper MBE who has asked us to speak at the Society's conferences, and the author Sally Pacholok who has mentioned my work in her book *Could it be B12? An Epidemic of Misdiagnoses* and invited me to write the foreword for the second edition.

May I also express my deep gratitude to the people of Horden and Peterlee, County Durham, UK, to the B12 Deficiency Support Group and its executive committee officers, and to all those kind people who have made generous donations since the charity and website were established.

## Author's Note

The information in this book is based on the knowledge and experience of the vital importance of vitamin B12 for human health gained over 40 years of clinical practice as a General Practitioner (family doctor), including 34 years of administering vitamin B12 therapy. It also draws on extensive research on vitamin B12 conducted by other experts. The aim of the book is to provide information for the public and clinicians alike in the hope of raising awareness of the widespread effects of vitamin B12 deficiency and how it may be treated. All patients whose names and photographs appear in this book have given full written consent for their data to appear in the hope that their experiences may help others. The recommendations given here are based on sound medical experience but are not intended as a replacement for advice from a health professional. We would always encourage patients to seek such advice, in order especially to rule out alternative diagnoses. The author cannot be held responsible for a patient's failure to seek professional health advice.

The list below summarises the key points made in this book:

- Vitamin B12 is a vital micronutrient, ranking in our view only after oxygen and water in the list of molecules essential for health.
- Vitamin B12 deficiency is common in the general population and can manifest at any age. Its prevalence is generally under-recognised. We found a prevalence of 18% in a medical practice population of 5,760 patients in 2015.
- Vitamin B12 is crucial for many body systems; the deficiency manifests in an array of different symptoms in different people.
- Pernicious anaemia is only one manifestation of vitamin B12 deficiency. In our view it is a late stage of vitamin B12 deficiency and may be preventable. Many B12-deficient patients do not have the symptoms of pernicious anaemia but have other symptoms.
- Contrary to accepted belief, the presenting symptoms are frequently neurological or neuropsychiatric and only rarely haematological.
- Many people are suffering severely and unnecessarily because of lack of recognition of this condition. Prompt treatment is essential to prevent irreversible neurological damage leading to patients becoming wheelchair-bound.
- Neuropsychiatric symptoms such as depression, anxiety, other psychological disorders and even psychosis, are common in vitamin B12 deficiency and there is evidence that the condition may contribute to the onset of dementia.
- Guidelines on how to diagnose the varied symptoms are severely lacking.
- The serum B12 test in common use has been shown to be unreliable as a stand-alone marker and commonly accepted thresholds for B12 deficiency are questionable.

- “Subtle” vitamin B12 deficiency is particularly difficult to diagnose but has the potential to deteriorate to a severe deficiency very quickly.
- Causes of B12 deficiency include genetic disorders of B12 absorption, insufficient dietary intake, any gastrointestinal illness (especially atrophic gastritis) or surgery, use of antacid medications and proton-pump inhibitors, and alcoholism.
- Vitamin B12 is necessary for several important metabolic processes and contributes to DNA synthesis through its interaction with folate. If these processes are disrupted due to lack of vitamin B12, serious illnesses can result, such as cardiovascular diseases and even cancer.
- Like folic acid, vitamin B12 is especially important during pregnancy to ensure a healthy child. Deficiency can lead to severe birth defects.
- Based on our experience over many years, we drew up and implemented a **Protocol for excluding B12 deficiency (Megaloblastic anaemia, pernicious anaemia) from adult and child presentation** in cooperation with the local Primary Care Trust which is given at the end of this book (see Appendix 1).
- Vitamin B12 deficiency is linked to autoimmune illnesses and can lead to Autoimmune Polyglandular Syndrome (APS). Another life-threatening illness, hypoadrenalism, is common in vitamin B12-deficient patients. As this is another under-recognised illness in which we developed some expertise, we also drew up a Protocol for diagnosis which is included at the end of this book (see Appendix 2).
- Vitamin B12 is non-toxic (even at very high doses) and cheap compared with many medications. Therapy with vitamin B12 would result in huge savings to the NHS. It will cure, in contrast to the symptom-modifying (often expensive) medicines that are frequently used to treat conditions which are in reality vitamin B12 deficiency.

## Introduction

This book is about vitamin B12 deficiency. This is an old illness – documented cases appear to go back nearly 200 years – and yet it is forgotten in the modern age of scientific medicine and pharmaceuticals.

**The greatest discovery of the last century in medicine was the discovery of penicillin and that it can eradicate, as well as prevent, life-threatening bacterial infection.**

**The most fascinating and far-reaching clinical discovery that I and my patients have encountered in our Practice over 34 years (from 1981 to 2015) is how a simple, harmless and cheap B12 vitamin can not only cure but also prevent a wide spectrum of diseases affecting each and every part of the human body and mind.** Vitamin B12 is so important that we would rank it as the third most vital element, after oxygen and water, for sustaining human life:

### *Table i-1 The order of importance of components vital to life*

<u>Physiologist's View</u>	<u>Our View</u>
1. Oxygen	1. Oxygen
2. Water	2. Water
3. Salt	3. Vitamin B12
4. Potassium	4. Cortisol
	5. Salt
	6. Potassium

Over more than three decades, I diagnosed, treated and followed up patients suffering from B12 deficiency at my medical practice in Horden, County Durham, collating data, auditing it and widely sharing this evidence-based knowledge. This has resulted in 100% patient satisfaction and there are around 300 testimonies to confirm it.

Based on this experience, this book presents new data, new findings and new understanding. The story must be told, and it is underpinned by evidence. Every case study, graph and table in this book tells the same story. It has been said that “the plural of anecdotes is not data” but can we really deny the overwhelming evidence of over 1,000 anecdotes concerning patients whom the author has cared for as General Practitioner (GP - family doctor), with illnesses all pointing towards a single underlying cause?

### **Towards a new paradigm**

It is our contention that the current paradigm which allows a diagnosis of vitamin B12 deficiency ONLY when macrocytosis and Intrinsic Factor (IF) antibodies are present needs to be changed. This paradigm is, in our view, based on limited understanding and pre-war clinical situations which, because of nutritional improvements, no longer apply. The modern-day presentation is different and diagnosis needs to take into account signs and symptoms which may be present even when macrocytosis and IF antibodies are not. More details of this much-needed crucial shift in diagnosis patterns are given in Chapter 2, and a new Protocol and guidelines for diagnosis and treatment are given in Chapter 3 and Appendix 1.

To quote another medical pioneer, Dr F. Batmanghelidj, MD:

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*“As an example, the understanding was that the Earth was flat. The new understanding is that the Earth is round...Adoption of a fundamentally significant new paradigm in the science of medicine is more difficult, even if the outcome is highly desirable and desperately needed by society.”*

***Your Body's Many Cries for Water*** (Batmanghelidj, 2008)

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I came to Horden/Peterlee to practice as a General Practitioner (GP) in 1970, and from that time saw a fruitful rapport between doctors and administrators working until 1997. Since then, in the last 20 years, the very sanctity of the holistic whole-person clinical care has been questioned and undermined systematically by NHS medical directors.

In the case of B12 deficiency, the lack of a holistic view has led to misdiagnosis or no diagnosis at all, resulting in serious irreversible damage to patients as well as distress and disappointment to their family members and dedicated carers. Conditions can deteriorate rapidly, with patients becoming housebound, wheelchair/crutches-dependent and without hope of recovery, if the autonomy of the GP is constrained in this way.

In order to put the discoveries that I and my patients have made into context, this introduction gives (in Part I) some autobiographical detail and explains how I first encountered the extensive effects of B12 deficiency. Part 2 describes the difficulties I had (and still have) in getting the findings accepted, and Part 3 describes our continued efforts to propagate the knowledge and our Patient-Safe Protocol. Then follow nine chapters, each dedicated to a particular set of vitamin B12 deficiency-related illnesses or a condition. Each describes our experience, with examples, and suggests treatments based on this experience. All patients named and/or photographed in this book have given their consent to publication (and many video testimonials can be found on the B12 Deficiency Support Group website: [www.b12d.org](http://www.b12d.org)). Other data are presented anonymously.

## **Part 1: Dr Joseph Chandy: journey to discovery**

### **Formative years**

I was born Joseph Alexander (“Chandy”) Kayyalackakom on 16 January 1941, in Kerala, south India. During the postwar period my parents were based in Thiruvananthapuram/Trivandrum, the capital of Kerala, lately known as “God’s own country”. I spent my formative years in this beautiful countryside.

Each day I could hear conversations between family and friends about the ongoing difficulties everyone was facing due to the long-term damage the Second World War had caused: disease, death and famine throughout the country.

During the same period, the independence struggle was gaining momentum and heartbreaking stories of human suffering could be heard from every part of the Indian continent, causing further sadness and concern. On 15 August 1947, to everyone’s joy and surprise, we heard the much-

awaited declaration that at long last our nation was independent, after 100 years of British rule. I was six years old and felt as though at long last my dream was beginning to come true. Unfortunately, my and the whole nation's joy was short-lived.

Months later on a calm quiet evening, the whole family was startled by the loud cry of many thousands marching through the main street and an inconsolable crowd weeping, beating their chests and lamenting as they came to know of the brutal assassination of Mahatma Gandhi, who was and still is the father of our nation. The entire crowd was repeatedly crying out "Who will answer for the blood of Mahatma Gandhi, who will answer for the blood of Mahatma Gandhi?" Hearing the people cry I began sobbing; I was inconsolable.

**This incident had a lasting impact on my relationship with my fellow human beings, especially my patients after I qualified as a Medical Practitioner in 1965. I have always remembered Mahatma Gandhi's words: "Mine may today be a voice in the wilderness, but it will be heard when all other voices are silenced, if it is the voice of truth" (Kumarappa, 1951).**

### Medical training and first prophetic message

I and the whole family were excited when I received the letter of admission to the Kerala Medical College.

Soon the day came to say "goodbye" to my parents, brothers and sisters and move away from my home town to the capital city. Looking me in the eyes, my father said (knowing that in six years' time I would be a qualified medical doctor): "I am blessed with 12 children, six boys and six girls, will one of you one day make a valuable contribution to humanity?"

I hope and pray that I have not disappointed my dear father who is watching over me from his heavenly home. I also believe that the Father God will greet me, and invite me with open arms into his heavenly kingdom as a "good and faithful servant" after an earthly life of service for 50 years (1965-2015).

### Encounter with B12 deficiency

In 1965 I qualified (MBBS in medicine) from Trivandrum Medical College, Kerala University (India). The following year I did my house physician's training under the supervision of a professor of medicine. Here I first encountered the effects of B12 deficiency.

In this city there were many Hindu Brahmin families who had been strict vegetarians all their lives. I noticed that some women between the ages of 20 and 30 presented in my outpatient clinic with a particular set of symptoms. Comparatively these women were quite fair in their complexion. All appeared pale, tired-looking and lacking in energy. They complained of aches and pains, headaches and dizziness. Having excluded other possible conditions, I was rather puzzled by these patients.

I sought my professor's guidance. His immediate advice was to give them weekly deep intramuscular (IM) liver extract injections which were painful. Eight weeks later, when they returned to the outpatient clinic, they appeared healthy and energetic and their pale faces had become pink and shiny.

I can recollect being intrigued and asking the professor how the liver extract could cause this remarkable transformation. My boss smiled and told me about the simple and life-saving discovery

made by George Minot and William Murphy of the US regarding the “Liver Diet” in 1926.<sup>1</sup> This discovery was accidental. While having lunch they gave their bleeding dog some leftover liver. A few days later they noticed that the dog’s bleeding had ceased. The two excited physicians decided to try the effect on chronically sick American soldiers. To everyone’s amazement, all these soldiers fully recovered. It was not until 1948, however, that the B12 molecule was officially isolated by Edward L. Rickes, Norman G. Brink, Frank R. Koniuszy, Thomas R. Wood and Karl Folkers in the US (Rickes et al., 1948b) and E. Lester Smith and F. Parker in the UK (Smith, 1948).

During this period, I was inspired by the unique British welfare state system and the formation of the state-funded National Health Service (NHS) in 1948, providing “cradle-to-grave” medical care for all UK subjects, rich and not so rich. This welfare system had become the envy of the world.

I decided to leave for the UK. When I sought my parents’ permission to leave, they asked me: “Why not practice in Kerala instead?” I gave two reasons:

- If I became an NHS doctor in England, I would not have to charge consultation fees from the rich or the not-so-well-off patients.
- In the UK I would be able to practice unhindered. The promise given by the then health minister, Aneurin Bevan, to the medical profession on 3 July 1948 had greatly influenced me: “My job is to give you all the facilities, resources, and help I can and then to leave you alone as professional men and women to use your skill and judgement without hindrance. Let us try to develop a partnership from now on” (Bevan, 1948).

### An unexpected prophetic message

On the night of 26/27 August 1966 I was travelling for the first time outside Kerala State; I was not at all used to airports or flights. In the 1960s the foreign exchange reserve of India was minimal so the maximum amount of money I was allowed to take with me was a mere three British pounds.

My aunt, who lived in Chennai, drove me to the airport, gave me a few instructions and led me to the international departures lounge. While I was settling down in the lounge, to my surprise, an announcement came across, “Dr Joseph Chandy, please come to the travel desk”. I was not expecting this added stress. I was anxious as to what it could be.

I walked towards the counter and joined the line. As the line began to move forward I noticed a respectable-looking senior gentleman moving forward, not in the line but on my left-hand side. Out of courtesy I asked him whether he would like to go in front of me. He responded “No, I will wait here,” and asked me whether I was Dr Joseph Chandy. I said “yes”.

Soon I reached the counter. The staff asked me whether I was prepared to give my seat to a family of five so that all of them could be seated in one row. I agreed, turned around and walked towards where I had been sitting in the lounge. To my surprise the senior gentleman was patiently standing at the same spot where he had said he would wait for me. I politely acknowledged his presence and

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<sup>1</sup> George R. Minot, George H. Whipple and William P. Murphy were awarded the Nobel Prize for Physiology & Medicine in 1934 “for their discoveries concerning liver therapy in cases of anaemia” (“George R. Minot - Facts”. NobelPrize.org. Nobel Media AB 2019. Sat. 9 Feb 2019. [https://www.nobelprize.org/prizes/medicine/1934/minot/facts/.](https://www.nobelprize.org/prizes/medicine/1934/minot/facts/)) See also Minot and Murphy (1926, 1983); NobelPrize.org (2016).

stood silent; he then began to speak: “I have an important message for you; listen to me, one day your discovery/work and your name will be spread all over the world”. He repeated the same message once more. I was totally bewildered.

I responded by saying, “Sir, I am in fact nobody, just a recently qualified doctor from Kerala setting off to the UK for higher studies and then hoping to return to Kerala to serve my local community”.

The gentleman kindly reminded me of what he had said earlier, “the important message”. Confused, I asked him who he was. He replied that he was the Professor of Neurosurgery at Vellore Medical College not far from Chennai. Only then did I realise that he was in fact the world-renowned Professor Jacob Chandy (my namesake).<sup>2</sup> What a privilege I thought, although still very confused. As he walked away, I returned to my seat. I felt almost as if I was dreaming. I looked again around the whole departure lounge; nowhere could I locate the mystery professor. Soon the announcement to the British Airways flight to London was relayed.

### First reported case of B12 deficiency without macrocytosis

So in 1966 I came to the UK and worked in paediatrics at teaching hospitals up to registrar level, passing my Diploma in Child Health (DCH) in 1969. Interestingly, at this time I came across a case of a rare condition, Waardenburg Syndrome, which presents as a tuft of white grey hair on the scalp of a newborn baby. There was previously no known cause for it. We now believe that this is a rare case of B12 deficiency causing vitiligo affecting hair follicles. (The baby was at the time of writing a teenager and still had the white tuft. Both mother and son have B12 deficiency and receive monthly B12 injections.)

This interest in maintaining the health of each person right from an early age continued after I became a GP. I had moved to the north-east to take up a post as a GP in a medical practice of 3,500 patients in Horden/Peterlee, County Durham.

It was by destiny that, ten years later, on 3 November 1981, I stumbled on my very first reported case of B12 deficiency with neuropsychiatric signs and symptoms, without macrocytosis (large immature red cells)<sup>3</sup> and without IF antibody being present. How this came about is described below.

One of my first assignments as a GP in 1970 was a call-out in the middle of the night to deliver a baby as the midwife could not get there. This event turned out to have momentous consequences for my future interest in vitamin B12.

Some time after the birth, the baby’s mother, Glenise Mason, came to my surgery suffering from anaemia. Her blood test showed microcytosis (small red blood cells), indicative of iron-deficiency anaemia, so I treated her in the normal way with an iron supplement. Her condition improved but the anaemia did not completely clear up and she presented at regular intervals over the next ten

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<sup>2</sup> Professor Jacob Chandy (1910-2007) established India’s first Department of Neurosurgery in 1949 at Christian Medical College, Vellore (Abraham, 2007).

<sup>3</sup> Macrocytosis, or enlarged red blood cells with a volume > 97 µl, occur where the red blood cells have not fully matured and are rounded rather than doughnut-shaped. This means they have a smaller surface area-to-volume ratio and cannot carry as much oxygen so the patient is tired all the time.

years with recurrent anaemia. Her persistent symptoms included extreme fatigue, low mood, breathlessness and weakness.

It was not until 1981 that it suddenly struck me that she had a similar look to that of the Hindu Brahmin women I used to treat successfully with the liver extract injection in India. I then thought of testing for B12 deficiency. At the time, such a suggestion was unheard of because Glenise did not have what were then considered the classic and only signs of vitamin B12 deficiency: macrocytosis and IF antibody. These are the signs of pernicious anaemia which were considered the only manifestation of vitamin B12 deficiency (a view which still lingers on today). I had great difficulty convincing the haematologist at the laboratory that the B12 test needed to be done, but eventually he relented. To our astonishment, the result came back of 185 nanograms per litre (ng/L) blood serum B12 – a level which clearly indicated deficiency. The result allowed me to make an immediate diagnosis and commence B12-replacement therapy by injection. The diagnosis was confirmed when symptoms receded, and Glenise returned to her normal active life.

This experience was a revelation, for it overturned accepted dogma and opened up an entirely new line of clinical enquiry: if B12 deficiency could occur without macrocytosis and IF antibody, then what other symptoms might it lead to? I realised that the implications were vast.

#### **Link between vitamin B12 and folic acid absorption**

As if this was not a dramatic enough discovery in itself, other important but previously unknown aspects of vitamin B12 deficiency began to emerge. The first was the link between vitamin B12 and folate. In the 1980s, the importance of folate was less well known so I did not think of supplementing Glenise with folic acid. Nevertheless, her blood test results showed that as her B12 blood levels rose, so did her levels of folate despite the lack of folate supplementation.

This revealed, crucially, that folic acid availability to the body is very dependent on the B12 status (see Table i-2). Note how closely both B12 (which was being injected) and folate (which was not being supplemented) availability in the blood serum follow the same pattern. Both rise to replete levels when B12 injections are given, and both fall rapidly (far more rapidly than the textbooks would have you expect) when injections are withdrawn. (Injections were withdrawn on various occasions because of Primary Care Trust (PCT) embargoes on treatment described below.)

**Table i-2 Relationship between B12 and folate levels in blood serum measurements**

Test	Dates of injections									
	03/11/81 <sup>1</sup>	17/2/92	25/3/94	13/2/02	14/3/02 <sup>2</sup>	7/1/04 <sup>3</sup>	9/6/04	11/1/05	21/4/06	25/6/09 <sup>4</sup>
Blood serum B12 (200-900) ng/L	185	775	>2000	731	904	257	628	1443	1664	639
Blood folate (8-20)	2.8	14.3	>20	18.6	15.2	4.7	9.7	7.5	7.6	5.1
TSH		0.90	0.98			0.97		0.53		
Haemoglobin g/dl	10.3	15.5	8.3	12.0				12.6		
Mean Corpuscular Volume (MCV) fL	79	89.6		89.4		88.1				

<sup>1</sup> injections started 1mg/ml every 1 month;

<sup>2</sup> 14/3/2002 injections ceased after this date due to Easington PCT embargo;

<sup>3</sup> 7/1/2004 injections recommenced due to lifting of Easington PCT embargo on existing patients;

<sup>4</sup> 14/3/2007 injections ceased due to County Durham & Darlington PCT embargo (embargo lifted 10/2/11).

**See also Charts in Chapter 5**

Folic acid absorption and utilisation seem to be almost entirely dependent on optimum availability of B12 in the circulation. The pattern in the table above is reinforced by many more patient observations. In this case, the patient’s folate levels responded to her B12 supplements even though there is no evidence that her dietary intake changed and 28 years of medical records show that she received B12 replacement but no folic acid or folate supplements. During each embargo period (see Table i-1 above - when B12 was not permitted to be given), her folic acid levels steadily dropped, and during B12 supplementation the blood levels of folate rose again (See also Chapter 5, Chart 5-1 which refers to the same patient).

**Genetic predisposition**

The second important aspect was that predisposition to B12 deficiency was inherited. In 1996, Glenise’s daughter, the very baby I had delivered, attended my surgery aged 26 manifesting similar symptoms without macrocytosis. Treatment was commenced, and this patient also recovered. In both cases I did not rely on the presence of macrocytosis and/or the positive IF antibody to be present in order to arrive at the diagnosis of B12 deficiency. This shows that the gene transcription defect is passed down from one generation to the next (see further examples in Chapter 5).

The above two cases led me to consider *the very first reported case of B12 deficiency without macrocytosis*; until then, macrocytosis was required before the doctor would even consider B12 deficiency. We now know that B12 deficiency can be easily diagnosed from symptoms, and

confirmed with the most basic empirical test: if supplementing with B12 relieves the symptoms, and failure to supplement or subsequent withdrawal causes the symptoms to return, then this is positive confirmation of the putative diagnosis.

My interest in vitamin B12 was kindled from that time on. As I began to research B12 deficiency I was surprised at the echoes down the centuries. Compare for instance these descriptions of symptoms:

*“Lightheaded, felt faint, dizziness, pins & needles, numb sensation in limbs, tired, sallow complexion, numbness & shooting pain down left leg, loss of grip.”* (Chandy in Glenise Mason’s clinical notes recorded 1981).

and James S. Combe reporting in 1824 the first medical description of a patient likely to be suffering from B12 deficiency -

*“His face, lips and whole extent ... were of a deadly pale colour ... languid; he complained of much weakness”* (Combe, 1824).

With this new understanding, despite the difficulties described below, over the next thirty years I was able to treat many patients who were suffering from B12 deficiency but whose blood test results did not show macrocytosis or IF antibody.

### Referral to secondary care (hospital consultant)

However, whenever secondary care (hospital endocrinology consultant, for example) referral was clinically felt necessary, in consultation with the patient and/or the family member, I made the referral promptly.

Patient choice is embedded in the NHS Constitution. There have been patients who felt that they had confidence in me and did not wish to be referred to secondary care, especially since other patients with the same symptoms had been into hospital and as a result had been left with no treatment and repeatedly called back for “observation” whilst they deteriorated.

I knew that I could confidently and safely diagnose and treat my patients but where the patient has required this, I have respected patient choice. By adopting the primary care protocols, my experience and specialist knowledge in many areas of general medicine steadily improved over many years. This resulted in my being able to diagnose and treat successfully many patients who were misdiagnosed or did not have a credible proven diagnosis, even when the misdiagnosis was made in secondary care.

## Part 2: Ups and downs

### My Pathway of Care and Information for Patients

Anyone who knows the UK NHS will know that the only certainty is change. In 2000, the NHS was restructured into Primary Care Trusts (PCTs), each responsible for an average population of around 100,000. Horden/Peterlee, where I worked, was included in the Easington PCT. (Following a national restructure between 2004-06, PCTs were eventually abolished in 2013.)

I had been successfully prescribing B12 supplementation since that first case in 1981, but in March 2002 Easington PCT delivered a blanket ban stopping me from making diagnoses of B12 deficiency.

This naturally affected a lot of patients whose symptoms immediately returned once the B12 in their system (from supplements) had gone. I recorded symptoms at intervals for hundreds of patients, including an extensive patient survey, so demonstrating to Easington PCT that the treatment should be reinstated. In July 2006, Easington PCT accepted my case studies and my **Pathway of Care and Information for Patients**, and reinstated the diagnosis and treatment of patients with B12 deficiency. The Pathway (which became the **Protocol** – see Appendix 1) was based on a highly detailed study of vitamin B12-deficient patients and vitamin B12 therapy. It was developed jointly with Easington PCT and overseen by Dr Jonathan Wallis, Consultant Haematologist at the Freeman Hospital, Newcastle-upon-Tyne.

Although the Pathway of Care was revised with agreement from the PCT a number of times, my difficulties did not end there. In what follows I describe a number of instances where my assessment of the most appropriate care for patients was rejected by the health authorities. For a second time, my B12 treatment was stopped and the Protocol rescinded.

### Referral to NCAA

On 2 September 2004 (eight months after reinstatement of the treatment pathway), the Chief Executive of the PCT wrote to me: “I am concerned both to secure the safety of patients and to safeguard your professional reputation as a doctor who has given outstanding service to his local community for over 30 years...However, I think we are at the stage that if you do not feel able to undertake a research project and you wish to continue your present line of treatment, then the only way I see of ensuring both patient safety and your professional good standing is to get advice from the NCAA”.<sup>4</sup>

The meeting with the NCAA was scheduled for October 2004. I requested whether I could bring a GP colleague, or if not, then the Chair of the B12 Deficiency Patient Participation Group (a lay person). The answer was “no” to both requests. I had three weeks to prepare my defence. I knew from past experience that it was likely that false allegations and misinformation would be presented to the panel during a pre-meeting. I realised my situation was quite serious. I did not have any influential colleagues I could approach for my defence. I felt in this dark moment that the only friend I had was my Lord.

Every Friday evening after surgery I entered the chapel, knelt and prayed, often with tearful eyes. At the end of my prayer, lasting one hour, my Lord prompted me in my spirit to pick up any Holy Bible I could find. To my amazement, on each Friday evening the same page was opened from different Bibles and the reading was exactly the same:

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<sup>4</sup> The National Clinical Assessment Authority (NCAA), renamed the National Clinical Assessment Service (NCAS) in 2005, works to resolve concerns about the practice of doctors, dentists and pharmacists. See <http://www.ncas.nhs.uk/about-ncas/>

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*“Listen! I am sending you out just like sheep to a pack of wolves. You must be as cautious as snakes and as gentle as doves. Watch out, for there will be those who will arrest you and take you to court, and they will whip you in the synagogues. For my sake you will be brought to trial before rulers and kings, to tell the Good News to them and to the Gentiles. When they bring you to trial, do not worry about what you are going to say or how you will say it; when the time comes, you will be given what you will say. For the words you will speak will not be yours; they will come from the Spirit of your Father speaking through you.”*

*Matthew 10:16-20 Good News Bible*

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I came home and remained silent until evening prayer time. Towards the end I opened the Bible the fourth time; my eyes led me straight to Psalm 23 verse 4 (King James Version):

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*“Yea, though I walk through the valley of the shadow of death, I will fear no evil: for thou art with me, thy rod and thy staff they comfort me”.*

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The following day the NCAA meeting was scheduled for the afternoon. My morning surgery was quite busy. At 11.30 am the supervisor telephoned and said that an important senior doctor wanted to see me immediately as the matter was urgent. The supervisor told him that I still had patients. “Never mind the patients, I want to see him now,” the visitor said. As it was lunchtime I asked the supervisor to have some tea and snacks ready. Within minutes the senior doctor was brought into my room. I stood up and respectfully asked him to be seated. He declined. I offered him some tea and snacks. He again declined and began saying, “I have come to warn you that if you promise to me now that from today you will not diagnose any case of vitamin B12 deficiency and will totally withdraw the B12 treatment regime you have been giving to all B12 deficiency patients since 1981, your job and your family will be safe and secure”. I fell to the chair and began to shed tears. Suddenly the crucifixion of Jesus came into my spirit. I responded to the visitor (senior doctor) as I had prayed the night before, with Psalm 23 verse 4. The senior doctor began trembling and asked me “will I be your rod and staff?” I replied, “yes, you will be my rod and staff”; he turned around and left the room.

On 26 October at 3 pm, following a pre-meeting where my case would have been discussed, the PCT Chief Executive’s secretary invited me into the boardroom. Almost for one hour they discussed not only the B12 controversy but all the past resolved issues. When I was asked to respond, I remained silent as I was commanded by the “word” I had received on the consecutive Fridays. To everyone’s surprise the senior doctor who came to warn me stood up and spoke on my behalf. On all counts he justified my actions. He challenged the panel and asked them whether any one of them had read my study/observational analysis (which had been widely shared as per GMC guidelines); no one answered “yes”. The senior doctor declared: “I read it last night; let me tell you, there is a gold nugget in his work. His protocol for B12d is not only safe: it saves lives”. One by one they all left the boardroom except for the senior doctor and myself.

## Rejection of my B12 deficiency work

In April 2006, six PCTs were merged to form a single PCT (the County Durham and Darlington PCT) covering a patient population of 600,000. The newly appointed Chair and the all-powerful medical director of the new PCT were fully aware of the existence of the former Easington PCT Approved Pathway of Care for B12 deficiency dated 3 July 2006.

Eight months later, on 14 March 2007, this officially approved Pathway of Care was unilaterally rescinded without any prior notice or consultation, or evidence being provided to support the decision. During the same period, an influential senior GP asked to see me urgently. When I questioned him the reason for the urgency of his visit, he replied: “[The new medical director] has already made up his mind to discredit your B12 deficiency study [approved by the former PCT]”. What was more, he said, following Professor Mike Pringle’s Investigation/Review (see below), the medical director would find reasons to suspend me and refer me to the General Medical Council (GMC).

I was in a state of shock. Fully realising the seriousness of the situation, my only remaining hope was to blindly trust in my Lord and Saviour. (All along, since I stumbled on the very first case of B12 deficiency without macrocytosis I had dedicated my work to my Lord Jesus.)

As I left home next day for the crucial meeting with the PCT, I decided not to tell my wife the threat we were under. On my way, I decided to step into the church to pray as a last resort. It was a rather cold, dark winter evening. I did not switch the light on at the church as I would be leaving soon. The parish priest thought a burglar had forced his way in to the church! I apologised for giving him a fright. I told him the reason I was there, seeking our Lord’s protection in this critical situation. Both of us knelt and prayed for a few minutes.

The moment I stepped out of the church my mobile rang. It was my son Paul from India. I briefly told him what was happening. He understood the gravity of the situation. Without any hesitation, Paul, with confidence in our Lord Jesus, declared: “Dad, you are an overcomer. Dad, you are an overcomer. Dad, you are an overcomer.”

As I walked into the surgery, to my surprise a priest and a gentleman were waiting to see me without a prior appointment. The supervisor told me the Irish gentleman had seen the BBC programme *Inside Out* about B12 deficiency<sup>5</sup> and had flown across to see me. I could not turn them away. They were satisfied with the consultation and the advice given for long-term wellbeing. At that point, I told them about the senior doctor waiting next door and what his agenda was. They were shocked by what they heard and prayed for me and reassured me.

After a few minutes, I invited the senior GP into my room. He told me bluntly that it was in my and the Practice’s best interests for me to resign immediately and hand over the Practice to my remaining colleagues. Then I told him about my spiritual encounter with the parish priest and

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<sup>5</sup> The BBC documentary *Inside Out*, featuring an interview with Dr Chandy, was broadcast on 31 October 2006. (Jackson, 2006)

prophetic message given by my son Paul. The senior doctor repeated again what awaited me if I did not follow his advice. I politely told him he could leave.

The effects on patients of the sudden withdrawal of B12 treatment through the rescinding of the officially approved Pathway of Care in March 2007 were dramatic, and we documented them.

We know that without B12, B12-deficient patients deteriorate steadily. However, when a patient receives B12-replacement therapy and then suffers a catastrophic withdrawal, the patient appears to deteriorate almost to the point they would have reached had they not received B12: deterioration after withdrawal is rapid. Many patients suffered and, sadly, one young mother developed double pneumonia and died. The number of patients suffering concurrently seems too much of a coincidence for us not to connect this death with the withdrawal of her regular replacement B12 injections for eighteen months, her immune system having thereby been compromised. This observation differs markedly from the proposed slow reduction in blood levels suggested earlier (Chanarin, 1979, 1980, 1982), and indicates how little we understand about the different efficiencies of different people to manage B12 in the body.

### Independent academic review recommendations

At the same time as instituting this latest sanction on diagnosing B12 deficiency, County Durham and Darlington PCT brought in an NHS auditor: Professor Mike Pringle (of Nottingham University and PRIMIS)<sup>6</sup> was appointed to scrutinise my B12 diagnoses and treatment and ensure that it met NHS standards of care.

Professor Pringle audited all of the patients identified by the Practice as exhibiting B12 deficiency and who had been receiving B12 supplements before the latest sanction – approximately 600 people. His team carried out a very detailed audit, interviewed patients, and met the patients as a group. The team applied their clinical knowledge as well as the interviews with patients to verify the patient information recorded and the changes that the Practice observed. The team concluded (in its report entitled *Vitamin B12 prescribing in the Shinwell Practice, Horden, County Durham*, dated 31 August 2007) that:

- The B12 protocol and actions in the Practice highlighted several important findings with regard to diagnosis and treatment of B12 deficiency. They observed that patients did feel a genuine benefit and this could not be attributed to a placebo effect.
- The PCT should provide extra ring-fenced funding to set up special dedicated B12 clinics to continue to provide this effective treatment.
- The PCT were to assist the Practice with audits, and support the Practice to provide data and share patients with independent researchers.

Following the advice of Professor Pringle, Shinwell Medical Centre was asked to participate in three research proposals backed by Manchester University and London University and the Durham and

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<sup>6</sup> Professor Mike Pringle CBE FRCGP was President of the Royal College of General Practitioners (RCGP) 2012–2015. PRIMIS is a University of Nottingham specialist organisation which provides advice on the capture, management, extraction and analysis of primary care data.

Sedgefield Research Body. Despite Professor Pringle's recommendations above, County Durham and Darlington PCT did not permit the Practice to be involved nor allow the Practice to advise patients of this research so they could apply independently.

After Professor Pringle's report was published, the ban on prescribing B12 was lifted but I was asked to keep meticulous records (which I had done anyway) and to submit them to the PCT every month.

### Consequences of misdiagnosis

B12 deficiency is not understood, and as a result, is often not diagnosed. We believe it is widespread, and patients may be diagnosed as suffering from a range of other conditions (such as those listed below) whereas the root condition may be B12 deficiency (this list is not exhaustive):

- Adrenoleucodystrophy (ALD)
- Adrenal leucomyopathy
- Adrenal fatigue
- Chronic fatigue syndrome (CFS)
- Depression/anxiety neurosis
- Fibromyalgia (FM)
- Functional dysphagia (swallowing difficulties)
- Inappropriate behaviour which could lead to a Functional Behaviour Assessment
- Functional paraparesis
- Functional movement disorder
- Functional neurological disorder
- Functional paralysis
- Hereditary spastic paraparesis
- Hysterical paralysis
- Idiopathic disturbance of gait
- Multiple sclerosis (MS)
- Munchausen syndrome by proxy
- Myalgic encephalomyelitis (ME)
- Psychosis
- Stiff person syndrome
- Semantic dementia

These patients are then prescribed lifelong toxic symptom-modifying and symptom-subduing medications, with a long list of harmful side effects.

We show here that robust clinically-based evidence has been presented by doctors and researchers (including the author), based on live patients, and has been offered to the responsible medical establishment time after time.

Unfortunately, representations from my local MP and patient representatives have been ignored repeatedly and there has been no willing or enthusiastic engagement. Transparent discussion is needed, to be followed by an action plan.

It does not take a medical genius to work out that with the deficiency-related presentation such as vitamin B12 deficiency or hypoadrenalism, it is unethical and clinically unsafe to carry out a placebo trial and deprive patients of safe treatment that could relieve their suffering. For example, if someone is suffering severe dehydration, it is not ethical to deprive them of water in order to see if they die more quickly. Unfortunately, during two separate periods of more than 15 months, our patients have been subjected to enforced withdrawal of B12 replacement.

This action by the PCT caused untold suffering to many, including the tragic and untimely death described above of a 41-year-old mother in May 2010 who was previously eligible and receiving parenteral vitamin B12 every month, and whose symptoms had abated. Many other helpless patients have developed irreversible physical, neurological and psychological damage. It makes me wonder if someone is profiting from this life-destroying agenda to obstruct the totally harmless replacement therapy, when a deficiency is clinically established. How would Aneurin Bevan respond if he returned and became aware of this deliberate destruction of human life by the same people who had given an oath to protect and preserve life when they signed up to be NHS doctors?

These two periods of enforced withdrawal of treatment demonstrate what would have happened had a placebo trial taken place. They demonstrate that there is no further need for placebo trials, that the withdrawal of this vital substance, this vitamin, causes the patient to relapse to their former symptoms. In short, it demonstrates that B12 deficiency is a real nutritional problem, and not in the imagination.

### **Establishing patient-safe ranges and guidelines at two levels**

If B12 deficiency is to be diagnosed from blood results, then some 'normal' ranges for the substances under test need to be established.

The most usual range accepted as 'normal' for serum B12 (B12 measurable in the blood) is 200 to 900 ng/L in the UK. There is some suspicion that this is actually the range of accuracy for the test equipment, and serves no biological function; 'normal' ranges are different in different parts of the UK, and appear to be different in different countries, and eminent researchers have called into question the accuracy of the current version of the blood test (Carmel & Agrawal, 2012; Hamilton et al., 2006; Nexo & Hoffmann-Lücke, 2011). Some hospitals in Japan use a higher reference range of 500-1300 ng/L.

There are instances where the long-established patient-safe ranges are altered in such a way that the level at which the deficiency can be diagnosed and treatment commenced is delayed indefinitely. As previously stated, this causes untold misery and often irreversible damage to patients' health and wellbeing. This is occurring with the following blood tests: B12, folic acid, ferritin, TSH, T4, T3, uric acid, cortisol, ACTH and antibodies, to name but a few.

Vitamin B12 deficiency, undiagnosed and untreated, can quickly lead to Subacute Combined Degeneration of the spinal cord (SACD). SACD was first identified over a hundred years ago (Russell et al., 1900), and is likely to be an early description of Multiple Sclerosis (MS). Prompt vitamin B12-replacement therapy reverses all the signs and symptoms of deficiency, including the neurological manifestations (Roessler & Wolff, 2017; see also Scalabrino, 2001) – and in our clinical experience, we have observed partial or complete remission from MS symptoms on a permanent basis. MS should be considered a description of the symptoms, and not the final diagnosis (see Chapter 6). It

gives no clues as to the course of treatment, whereas vitamin B12 deficiency is much more specific and helpful.

Several of the previously listed misdiagnosed diseases can be prevented by preventative treatment from the beginning of life and at the pregnancy stage of the mother. For example, the mother should be screened for vitamin B12 deficiency, rather than wait until her child develops syndromes or diseases as infant, teenager or adult, which may by then be untreatable.

It is our belief that the NHS should try to proactively overcome diseases such as dementia and cancer by giving the human embryo the best possible chance. Mothers could begin with vitamin B12 supplementation as soon as a pregnancy is planned (see Chapter 5).

### The topsy-turvy world of Patient Care Protocols

Some of the difficulties derive, in our view, from the diagnostic method which does not allow for a “whole person” approach.

For example, a patient presents with tiredness, anxiety, low mood and headaches. The clinician is required to use a standardised Patient Health Questionnaire (PHQ 9 form), completed by the patient. If he or she has scored high, the diagnosis of depression is required. The patient accepts the prescription for an antidepressant, which is followed by further mandatory reviews (which will earn more money for a GP practice). Because of the ubiquity of the PHQ 9, the patient’s personal history, family history, and the possibility of other conditions such as a nutritional deficiency are not considered or explored with the patient.

Similarly, many of the syndromes listed above can represent other conditions such as underactive thyroid, B12 deficiency, ferritinaemia, or hypoadrenalism. However, diagnosis of these conditions does not attract achievement points for practice (QOF); the GP’s autonomy as clinician is being eroded because of conflict of interest.

Misdiagnoses made predominantly by secondary-care clinicians (hospital doctors) include CFS, ME, FM, MS, functional paralysis, etc. These are perfect descriptions of symptoms, but it is a smoke-and-mirror effect. Following commencement of toxic symptom-modifying or symptom-subduing medications, every one of these unfortunate patients is being referred to nurse-led no-return clinics, to modify the symptoms, with no expectation of treatment or recovery.

We therefore explore the challenges, and propose a Protocol for diagnosis and treatment in Chapter 3 and Appendix 1.

### Part 3: Sharing the knowledge widely

In 34 years of vitamin B12 experience and observations I amassed a great deal of knowledge which I have aimed to share in many different ways in conformity with the General Medical Council (GMC) guidelines on propagation of knowledge. Since 1981, I have engaged in debates, written to parliament, given presentations and educational workshops and spoken about B12 deficiency at many national and international conferences in Britain, India, Denmark and France, including the conferences of the Pernicious Anaemia Society (see list in Box i-2). My work and two of my patients were featured in the BBC documentary *Inside Out* broadcast on 31 October 2006.<sup>5</sup> In addition to collating two substantial patient surveys documenting the symptoms before and during treatment,

and during a period of treatment withdrawal, I have also responded (and still respond) to enquiries from doctors, paramedics and patients all over the world about ways of diagnosing and treating B12 deficiency.

Other important work has included assembling evidence for submission to various regulatory authorities responsible for medical care guidelines. As described above, I conducted a retrospective study (1981-2006) on vitamin B12 deficiency in patients with neuropsychiatric symptoms and prepared a *Pathway of Care and Information for Patients* for the PCT (Chandy, 2006b). This study was also submitted to the British National Formulary (BNF) board. The BNF has since changed its guidelines, for example to remove any recommendation for use of cyanocobalamin (which it describes as “less suitable for prescribing” (BNF, 2017)), and to increase the recommended frequency of injections from three- to two-monthly for neurological conditions.

In early 2007, I wrote to the BNF editorial board, the House of Commons Health Select Committee and the editor of *The Times* to alert them to the risks associated with undiagnosed B12 deficiency in expectant mothers and the danger of homocysteinaemia and its consequences. If the mother has undiagnosed B12 deficiency, and is untreated or only given folic acid supplement, there is a risk that she could deliver the child with neuromuscular damage, SADC, congenital abnormalities, tumours (including brain damage) and spina bifida. This can be avoided with vitamin B12 replacement before and during pregnancy (Molloy et al., 2009).

BNF Guidance on treating newborns to eighteen-year-olds with vitamin B12 has since been published (BNFC, 2008). We believe that this came about as a result of our submission with a retrospective study.

I also wrote to the National Institute for Care and Excellence (NICE), in July and September 2014, concerning the lack of NICE Guidelines on vitamin B12 deficiency and hypoadrenalism. I requested a ‘Patient-Safe Guideline’ for vitamin B12 deficiency on the basis that a **pathway had been jointly prepared and approved by Easington PCT in July 2006**, eight years earlier, based on clinical evidence gathered over 25 years since 1981.

However, at the time of writing there is still no NICE Guideline available. This issue is addressed in Chapter 3.

### The B12 Deficiency Support Group

I found that I was not alone. Concerned at the widespread ignorance and dismissal of this condition by the medical profession as a whole and its frequent misdiagnosis, a group of patients suffering from B12 deficiency at our Practice set up the B12 Deficiency Support Group which was later converted to a charity.<sup>7</sup> Its mission is to provide a voice for the sufferers and help them gain the support, guidance and treatment they require.

### Cost savings to the NHS

NHS resources are under strain. Prevention is the key to a cost-effective health service which also delivers quality care for the population and improved economic output to the nation. Prevention requires planning, and the right mechanisms to be implemented in the first place. It has been

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<sup>7</sup> Registered charity number 1146432. Further information is available from <http://www.b12d.org>.

calculated (figures from 2010) that failure to diagnose B12 deficiency is costing the NHS a minimum of £894 million per year in medical care required, quite independent of the additional social care, the loss in economic output for British commerce, and the damage to people's lives caused (Minney, 2010).

### Our Patient-Safe Protocol

I am recommending tried and tested **Patient-Safe Protocols** that we have developed for diagnosing and treating B12 deficiency and hypoadrenalism. The respective Shinwell Medical Practice protocols for both conditions are in the appendices for your reference. Discussion and results of our treatments showing the long-lasting reversal of patient's conditions are found in the ensuing chapters. Other testimonies can be found on the B12 Deficiency Support Group's website.

We developed this Protocol following the recommendations in *Harrison's Principles of Internal Medicine* (Babor & Bunn, 2005; Hauser & Goodin, 2005, 2008; Hoffbrand, 2008) and United Kingdom National External Quality Assessment Scheme for Haematologic Assays (NEQAS) which advise that it must be a clinical decision to undertake a therapeutic trial in the suspicion of cases when a patient presents with classic signs and symptoms of B12 deficiency. See also up-to-date information in BMJ Best Practice (2018d).

The emphasis on the importance of the clinical picture is shown in the 20th edition of *Harrison's* which states (p. 701): "An important clinical problem is the non-anemic patient with neurologic or psychiatric abnormalities and a low or borderline serum cobalamin level. In such patients, it is necessary to try to establish whether there is significant cobalamin deficiency... A trial of cobalamin therapy for at least 3 months will usually also be needed to determine whether the symptoms improve" (Hoffbrand, 2018). NEQAS similarly states: "In the event of any discordance between clinical findings of B12 deficiency and a normal B12 laboratory result, then treatment should not be delayed. Clinical findings might include possible pernicious anaemia or neuropathy including subacute combined degeneration of the cord. We recommend storing serum for further analysis including MMA, or holotranscobalamin and intrinsic factor antibody analysis, and treating the patient immediately with parenteral B12 treatment" (NEQAS, 2014).

Similarly, the British Society for Haematology states: "The clinical picture is the most important factor in assessing the significance of test results assessing cobalamin (B12) status since there is no gold standard test to define deficiency". The Society reiterates that "Definitive cut-off points to define clinical and subclinical deficiency states are not possible" (Devalia et al., 2014).

Along with these protocols I advocate a holistic all-person (mind, body and spirit) approach to good medical care in place of the modern tick-box clinically unsafe methods.

### Importance of holistic care: Mother Teresa's influence

The importance of caring for the whole person was brought home to me in my early days as a young medical student when I worked with the Mother Teresa mission among poor fishermen's families in the slums of Kerala, and later through my experience with one particular patient, Mr Norman Imms.

I had joined the mission after developing vitiligo which had a devastating psychological effect on me and led me to search for answers in prayer and charitable work. Working with poor families taught me to respect the poor, the sick and their suffering. To my surprise, after a few months my own

health improved. This experience proved to be very valuable some years later when I was practising as a GP in County Durham and encountered a patient with particularly challenging problems. Mr Imms had been diagnosed as a paranoid schizophrenic manic depressive, also suffering psychosis and psychopathy. He had been removed from many other GPs' lists but over 17 years he was a daily visitor to my surgery, also demanding night-time consultations. I endured these visits because I felt that someone needed to help this poor man. Eventually, in 1990, I told him that I could not continue his care and that the only way to obtain help was for him to "spiritualise" his illness.

***Figure i-1 Dr Chandy meets Mother Teresa***



Photo © Norman Imms

He came with me to visit Mother Teresa and then wrote to her and was accepted as a co-worker. He met Mother Teresa 10 times in all. Each time his condition improved. On the last occasion, in 1997 not long before her death, she told him he was cured. This had a dramatic effect on him. When I next saw him he was truly a changed man: his hallucinations and delusions were completely gone. This taught me that a "true physician ...must not only heal the body, but also touch the mind, and that the inner spirit of a human being is the most important part" (Independent, 1999).

This miracle prompted me to write to the Vatican to support the case for Mother Teresa to be made a saint. Mr Imms and I also participated in a BBC "Big Question" debate entitled "Does Mother Teresa deserve sainthood?" in October 2009. Mother Teresa was declared a saint in 2016.

## What B12 therapy means to our patients

Each of my patients is saying “Doctor, you gave me my life back!” Every single patient has his/her own story to tell about how ill they were when their B12 level was low, and how well they are now with their B12 level normal. I would like to emphasise that it is not me, it is the result of a caring and logical approach to medical treatment in keeping with the Hippocratic Oath, the promise by all clinicians: *“May I always act so as to preserve the finest traditions of my calling and may I long experience the joy of healing those who seek my help”*.

There is perhaps no clearer way of communicating the difference this approach can make than by ending this Introduction with these heartfelt words from an appreciative patient:

*“Hello Dr Chandy*

*Not many people have a day in their life that is quite as inspiring, uplifting and as full of love and care as yesterday, but that is what it was for Elise and me.*

*We wearily wended our way back to Northallerton, and then I drove home back to Sedgefield with more hope in our hearts than we have had for over four years. Thank you does not seem adequate for the huge amount of time you spent with us, and I will never forget the hug you gave me as we departed – a wonderful memory that will stay with me forever.*

*Today I start getting us well, by getting the various tests put in place, ordering sharps, B12 etc and if you don't mind I will keep you updated with results etc.*

*With the greatest respect and thank you to a very special man.”*

*Pauline Tweddell, 3 November 2016.*

### **Box i-1 Dr Joseph Chandy: Timeline**

1941, 16 January	Born Kerala, India
1965	Qualified MBBS, Trivandrum Medical College, Kerala University (India).
1966, June- August	Tutor, anatomy, Medical College Hospital, Allapy, South India.
1966, 26/27 August	Arrival in the UK and employment by the NHS. Prophetic message from the late Professor Jacob Chandy (1910-2007), world-famous professor of neurology at Christian Medical College, Vellore, India.
1966-69	Worked in paediatrics and general medicine in UK hospitals.
1969	Awarded Diploma in Child Health, Glasgow University.
1970	Appointed General Practitioner and senior partner to Shinwell Medical Practice, Horden, County Durham, UK.
1981	Encountered first case of vitamin B12 deficiency without macrocytosis or anti-IF antibodies.
1981-2002	Successfully treated many vitamin B12-deficient patients.
1988	Purpose-built a modern GP medical practice/nursing home complex in the heart of an ex-mining community, providing 50 new jobs. This won the Royal Town Planning Institute's Design Award for incorporating innovative adaptations so that the sick and disabled patients can help themselves.
1997	Meeting with Mother Teresa in Denmark.
1998-2005	Primary Care Group Board Member – elected to represent local GPs.
2002, March	Easington Primary Care Trust (PCT) delivered a blanket ban on my diagnoses of vitamin B12 deficiency in any patient whose B12 level was above the local laboratory threshold of 180 ng/L. The embargo remained in force until 2003.
2004, January	First draft of a <i>Pathway of Care and Information for Patients</i> regarding vitamin B12 treatment.
2004, 12 February	Easington PCT imposed an embargo on vitamin B12 treatment for new patients. The embargo remained in force, with some modifications, from 12 February 2004 to 3 July 2006.
2004, 2 September	Letter from Chief Executive of Easington PCT and referral to National Clinical Assessment Authority (NCAA).
2004, 26 October	Meeting with NCAA.
2006, 3 July	Joint work with the PCT on updated version of <i>Pathway of Care and Information for Patients</i> regarding vitamin B12 treatment overseen by Dr Jonathan Wallis

	(Consultant Haematologist, the Freeman Hospital, Newcastle-upon-Tyne). The Pathway was accepted by Easington PCT on 3 July 2006.
2007, 14 March	<i>My Pathway of Care and Information for Patients</i> was unilaterally rescinded by the new County Durham and Darlington PCT. This second embargo remained in force from 14 March 2007-10 February 2011. The PCT appointed Professor Mike Pringle to conduct an independent academic review of my work.
2007, 31 August	Professor Mike Pringle's report entitled <i>Vitamin B12 prescribing in the Shinwell Practice, Horden, County Durham</i> , dated 31 August 2007, highlighting my findings, recommended that the PCT provide ring-fenced funding to set up special dedicated clinics to continue to provide this "effective treatment". The report asked the PCT to assist the Practice with audits and support the Practice in sharing data and in sharing patients with independent researchers.
2009, 1 August	<i>My Pathway of Care and Information for Patients</i> was partially accepted by County Durham and Darlington PCT which allowed treatment to recommence for some categories of B12-deficient patients.
2010, 25 September	Received Glory of India Award for a lifetime of service in primary care and work on vitamin B12 deficiency.
2011, August	Shinwell Medical Practice develops its own <i>Protocol for excluding B12 deficiency (Megaloblastic anaemia/Pernicious anaemia)</i> from adult and child presentation based on the former <i>Pathway of Care and Information for Patients</i> .  <b>The Protocol is given in full in Appendix 1 of this book.</b>
2015	Retirement from the NHS.

### ***Box i-2 Presentations to raise awareness of B12 deficiency***

1. Postgraduate meeting – Durham.
2. Research Interest Group – Sedgefield.
3. Paper on 'B12 deficiency with neuropsychiatric signs and symptoms with or without anaemia or macrocytosis' given at Northern Primary Care Research Network organised by Royal College of General Practitioners North of England Faculty Annual Research Presentation Day, Collingwood College, Durham, 16 November 2006.
4. Presentation to PCT board and Executive Committee – Durham.
5. Presentation to Professor Mike Pringle CBE (former President of the Royal College of Practitioners) at the Shinwell Medical Practice, County Durham.
6. Major International Research Conference organised by Pernicious Anaemia Society of UK - Bristol.
7. Annual Presentations at the Pernicious Anaemia Society, UK – Bristol.
8. Postgraduate Education Meeting – Sunderland.
9. Postgraduate Education Meetings – Peterlee and Easington District.
10. Postgraduate Education Meeting – Hartlepool General Hospital.

11. Presentation at a large conference - Denmark
12. Presentation – Delhi; India which was widely covered by the media both locally and nationally
13. Presentation – Kerala, India; again, widely published by the media
14. Postgraduate workshop – Kerala, India.
15. Poster Presentation B12d - BMJ: Future of Health Conference, London.
16. Poster Presentation on hypoadrenalism at *the Biannual International Forum on Quality and Safety in Healthcare*, Paris.
17. Participation in BBC documentary *Inside Out* broadcast on 31 October 2006.
18. Paper entitled 'Doctor, you have given me my life back' given at first international conference on B12 deficiency (*Congress B12 Integral "Cobalamin4All"*) held in Driebergen, the Netherlands, 28 May 2010.
19. Debate on Vitamin Supplementation; was one of four guest speakers – Westminster, London.
20. Paper entitled 'A Protocol for B12 Diagnosis and Treatment by Primary Care Clinicians' given at the Pernicious Anaemia Society symposium and study day in Porthcawl, Wales, June 2011.
21. Lecture tour of India, 2014.
22. Poster Presentation on B12d - 'Vitamin B12 deficiency, a common but forgotten illness'. *International Forum on Quality and Safety in Healthcare*. Paris, France, 2014.
23. Paper on "B12 deficiency and APS with a causal link to hypothyroidism, adrenal insufficiency." In *Thyroid Patient Advocacy Conference*. Crown Hotel, Harrogate, North Yorkshire, UK, 2015.