



UNIQUE CARTOON BOOK TO UPLIFT/EDUCATE CHILD DIABETICS



Dutch psychologist and educational material developer, Cobi de Jong, star of the new DVD movie, *You, me and Diabetes*, Fidhili Kinasha and President of Diabetes South Africa, 'Oupa' Gumede, at the 19th World Diabetes Congress in Cape Town in early December last year.

Picture: Chris Bateman

A unique cartoon book called *Snuffles, the Rabbit with Diabetes*, plus a DVD movie on the life of his 11-year-old schoolboy counterpart is set to fill an aching educational need among the 11% of South Africans directly affected by the disease.

Shocked by the dire lack of age-appropriate educational material for children with type 1 diabetes in this country, Dutch psychologist Cobi de Jong arranged for the book, written by her 26-year-old diabetic daughter, Hiske, to be translated locally.

Hiske began displaying the symptoms of type 1 diabetes at the age of 10 years. Not long after arriving in Pretoria with her Dutch Consul General husband in 2002, De Jong, who specialises in diabetes counselling and is a trailblazer in holistic support for patients in Holland, contacted leading paediatric endocrinologist, Jacobus van Dyk.

Van Dyk, who practises at the Little Company of Mary Hospital in Pretoria,

was enthusiastic about the idea. He confirmed the paucity of such material in the country. Together they founded Kids&Care South Africa, an NGO aimed at producing educational programmes and material on how best to manage the disease in a holistic manner, for children, their parents and their peers.

'The basic aim is to improve the quality of life for these children and to increase awareness of this pandemic,' Van Dyk told *Izindaba*. Long-term living with the disease without proper support led to a loss of self-confidence and a sense of alienation from friends and family, not to mention morbidity and mortality.

Rural diabetes patients worst off

Speaking at the launch of the book and DVD at the 19th World Diabetes Congress in Cape Town in December last year, Van Dyk said it was a struggle in this country to achieve optimum treatment for diabetes without compromising quality of life.

A holistic 'team' approach including a specialist, dietician, psychologist and family/peer group support was not always possible.

With only five main metropolitan centres carrying decent treatment facilities, most people suffering from diabetes had to rely on remote clinics staffed by inappropriately skilled clinicians and nurses. 'The traditional model of prescribing treatment is not always in line with the realities,' Van Dyk stressed.

Kids&Care aim to address this by distributing educational material nationwide, supporting and building half-way houses for recently diagnosed children and 'reaching out to other African countries'. So far they have published *Life – You and your Child with Diabetes* in Afrikaans and English, *Dia...What?*, a workbook in English, Afrikaans and Zulu, while *Snuffles, the Rabbit with Diabetes* is currently available in English and Afrikaans, with translations into Xhosa, Sesotho and Zulu due next year.

Most people suffering from diabetes had to rely on remote clinics staffed by inappropriately skilled clinicians and nurses.

Says Esther Hesli, the fellow Dutch psychologist who collaborated with De Jong to advise the author and compile the teacher/parent advice sections at the end of each chapter in the *Snuffles* book: 'Firstly we wanted to help very young children integrate diabetes in their lives – they are too young to understand the reasons behind the regimens. Secondly, children recognise their own experiences in the book, like going to a birthday party and having to deal with lots of snacks when you cannot eat them.'



It was crucial that parents were supportive and learnt to talk about the disease to their kids. The book gives parents 'practical handles' to manage the disease in their daily family lives.

Hugely user-friendly

The psychologist pair conducted a scientific study on Dutch parents who were given the book and discovered that the 'vast majority' used it regularly. Their next book will be for schoolteachers to use in their life skills classes so they can educate non-diabetic pupils.

The Dutch-funded Marang House in Johannesburg, founded by the late Dr Pieter Ernst in 1998, caters for children suffering from chronic complications associated with renal failure, cancer, diabetes, burns and/or trauma. Marang's board of directors and Kids&Care aim to set up similar homes throughout the country. Marang House in Northcliff accommodates 11 patients at a time, aged 4 - 14 years, and has overseen the recovery of 35 children, some 70% of whom Dr Cecil Levy of Johannesburg Hospital estimates would not have survived otherwise.

Marang (seTswana for ray of sun or hope) House is aimed at children whose parents cannot afford constant medical care, supervision and accommodation in an environment best suited for

overcoming chronic illnesses. More than 60 children have recuperated, learnt and played at the home in its 8 years of operation. Some spend up to 3 years there before resuming a 'normal' life again.

From diagnosis to feeling faint in class, collapsing on the soccer field and learning to self-medicate and/or eat glucose-bearing food correctly to scoring the winning goal in a soccer tournament, the 11-year-old Fidhili and his fellow pupils turn in an invaluable performance.

'Oupa' Gumedde, President of Diabetes South Africa, himself a late-developing diabetic whose mother was diabetic and who lost two maternal aunts to the disease, said the latest book and DVD filled a 'major void in this country'.

'We need to market this material to every clinic and district hospital. Diabetes is often stigmatised. When people see you pricking yourself and drawing blood they think you're doing an HIV/AIDS test. With 5 million South Africans affected by this disease, you can imagine the impact these kind of materials can have.'

A diabetes star is born

The DVD movie, called *You, Me and Diabetes*, traces a typical week in the life of Fidhili Kinasha (11) a grade 5 pupil at Crawford Preparatory School, situated a stone's throw away from the Little Company of Mary Hospital in Pretoria. The Tanzanian-born Fidhili plays the part of a diabetes type 1 sufferer with great authenticity. His supporting cast is the entire Crawford school community that turned the making of the film into an educational project.

From diagnosis to feeling faint in class, collapsing on the soccer field and learning to self-medicate and/or eat glucose-bearing food correctly to scoring the winning goal in a soccer tournament, the 11-year-old Fidhili and his fellow pupils turn in an invaluable performance.

Dr Wim Wientjens, Vice President of the International Diabetes Foundation, described the DVD as 'absolutely unique in South Africa, there was nothing like it before,' and saluted those involved.

For more information, see www.maranghouse.com and www.kidsandcare.co.za

Chris Bateman