Carolina Neves – Deputy Clinical Director, APDP, Portugal

> Science is doing its part in bringing amazing developments forward. We need to work on creating a world where politics follow science and pursue people's well-being

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APDP is the association for people living with diabetes in Portugal, and the oldest such institution in the world. Deputy Clinical Director Dr Carolina Neves emphasises the APDP's patient-centred approach to integrated diabetes care, its role in advocating for greater accessibility to treatments, why obesity treatment should be built into diabetes strategy, and the importance of early intervention and advanced therapies in managing healthcare system costs in the long run.

Could you introduce yourself to our international audience and outline the work you are doing at the Portuguese Diabetic Protection Association (APDP)?

I am an endocrinologist and have been a specialist since 2016, joining the APDP in 2017. My clinical activities are dedicated to general diabetology, insulin pump therapy, rare diabetes, obesity and endocrinology. Besides my clinical activity within the APDP, I am a diabetes trainer in several APDP courses for health professionals and the coordinator of the advanced course on type 1 diabetes. In addition, I am responsible for rare disease conditions at the APDP. 2 years ago, I was invited to join the APDP's clinical leadership team. As deputy clinical director at the APDP I have been involved in defining strategies and planning solutions for our health services optimisation as well as our social causes. Overseeing all patient care operations and programmes as been a thrilling and challenging experience.

The APDP was founded in 1926 and is the oldest diabetes association in the world, having been set up when insulin was discovered and showed results in patients. The first mission of the APDP was to deliver treatment to all patients for free, however it also soon became about providing education on how to use insulin and the important aspects it involves for patients' safety and better clinical outcomes. The APDP became a centre to fight for people with diabetes and we still undertake these tasks today.

We have an outpatient centre at the APDP that gives care to people with diabetes and a school to educate families, patients, carers and healthcare professionals. We are a social non-profit organisation that has been fighting for the reimbursement of diabetes treatments, and although we initially started with that being focused around insulin only, it has evolved to areas such as glycaemic monitoring devices and now to insulin pumps, which are still are not available for all Portuguese patients.

Our healthcare model is patient-centred, focused on the needs of people with diabetes, taking into account specialists such as diabetologists, nephrologists, ophthalmologists, endocrinologists, podiatrists, cardiologists, gynaecologists, urologists, psychiatrists, psychologists, nurses, nutritionists, and paediatric departments and dialysis machines. Retinographies and retinal angiographies are performed in our clinic, as well as most ophthalmologic surgeries. We have our own laboratory and imageology department. We work with the public health ministry to provide the health services that are contracted under a protocol that has been established to attend the public's needs. Patients are referred by their family doctors to benefit from this public service access. However, anyone can be assisted by the APDP since we are not exclusive to the public system. Our outpatient clinic has had international visitors, who are very welcome, interested in studying our model of fully integrated care.

At the outpatient clinic located in the centre of Lisbon we treat more than 13,000 patients per year and undertook more than 50,000 clinical visits in 2022. But we would like to extend our services to more distant geographic areas. As diabetes prevalence grows, we believe in the future of small diabetes outpatient clinics dotted around the country that would benefit our population not only by providing specialised healthcare, but also by providing more education on prevention and diabetes care.

Besides our clinical mission, we fight for the rights of people living with diabetes. One more example is achieving what is known as the "law of forgetfulness," through which patients with diabetes do not have to declare this to their insurance companies, preventing them from being discriminated against. All in all, we are lobbying and advocating for people with diabetes in the public space and behind closed doors, as well as pushing for a greater reach at universities and national institutions.

Governments have been known to feel that advocacy groups are being pushed by the industry, which can cause conflict. What is your view on this relationship in Portugal?

We are hired by the public healthcare system for our services and we act as consultants for the government to give our opinions and defend what is the best for patients. We do not work for the commercial industry but obviously we do have interactions with it. This is natural in such a field.

Insulin is a technology that is now nearly 100 years old. How open is Portugal to bringing in new innovations within the field of diabetes?

Our country is open to new innovations not only with respect to insulin, but also for many other new drugs that are causing a change in prognosis for this chronic disease. We should distinguish between type 1 diabetes, which is totally dependent on insulin therapy, from type 2 diabetes that is the target for many new efficient and safe molecules.

Type 2 diabetes is the most common kind of diabetes and, in its complex physiopathology, insulin resistance is one of the main mechanisms that along with beta-cell dysfunction might evolve into insulin deficiency. The increasing prevalence of obesity and weight problems are responsible for most cases of type 2 diabetes. If we were to eliminate obesity, 80 percent of diabetes cases would not exist. Therefore, one of the pillars of diabetes treatment and prevention is weight reduction and control, for which new medication has been appearing and has already demonstrated high efficacy and safety. Although we still have a need for insulin therapy in this type of diabetes, we expect it to be postponed for later in the natural course of the disease as these new drugs allow for better glycaemic control and a longer insulin-free treatment period.

If we can fight the disease at earlier stages, before it comes to the point of requiring insulin, then treatment of patients will be easier and they will live a better quality of life with less complications.

On the other hand, the new insulin analogues are becoming closer to physiological insulin secretion and more adapted to patient's needs, safety and comfort which makes insulin therapy more flexible and easier nowadays.

The new medications are very good for treating early-stage patients without insulin, but they are quite expensive. We may say the same about new technology and devices that contribute to better metabolic control and quality of life. However, it is fundamental that policy-makers acknowledge that the long-term costs of these therapies is less than that of waiting until the patient has cardiovascular, renal, ophthalmologic and other complications. Moreover, a long-term well-planned strategy for diabetes will not only save direct costs on health, but also have an impact on indirect costs as people are able to maintain a role in society, meaning the patient can work and live a good and independent life.

How prominent are the APDP's campaigns today?

The APDP has promoted several campaigns for diabetes screening and risk evaluation, retinopathy and diabetic foot screening and disease prevention among many others. One of the latest has been a campaign for the right to hybrid closed loop system insulin for everyone with type 1 diabetes. This campaign has been successful in bringing the issue to a debate in parliament and we are now waiting for the government to fulfil its promise.

Last November, the APDP promoted a meeting with parliament to put together a national plan for diabetes. It was called the "Diabetes Drama" and was based on the European resolution for diabetes. It did not only involve the Ministry of Health, but also parliamentary commissions such as agriculture, budget, labour, education, physical activity, environment and city planning, among others. Most determinants relating to health were discussed, but we need the whole society to be shaped around preventing diabetes and a big part of that is preventing obesity.

The pharmaceutical industry has been abuzz with the obesity drugs being brought onto the market. What is your opinion on these treatments?

In 2004, Portugal was one of the first countries to recognise obesity as a disease, the main risk factor for diabetes. However, obese people are still not treated like people with a chronic disease. 28.7 percent of the population is obese and if you include those that are overweight it sits at around 67.6 percent, so around two-thirds of the population. That means all these people are at risk of diabetes and we should consider the reimbursement of obesity treatment and prevention of obesity as part of the diabetes strategy. We do have programs for nutrition and physical activity but we need to attack the obesity disease at an early stage before the problems progresses to later complications. The scenario is pretty similar here in terms of obesity prevalence to the rest of Europe, but again reimbursement is only for diabetic therapies and not for obesity treatment.

We should rethink the way we treat obesity. With our multidisciplinary teams we should have departments that are specialised in obesity treatments. These teams would use evidence-based medicine to be able to approach and assess patients and prescribe treatments based on clinical evaluation and judgement. These patients should then be monitored adequately so that weight loss and lifestyle changes are both goals of the treatment and long-term follow-up prevents the weight regain.

In Portugal more and more people are also going to private practices, and the private hospital field is becoming big business. We need more regulation around obesity treatment prescriptions to prevent inappropriate use, a factor that is preventing these medications from being reimbursed for those who have the evidence-based medical indication for them. It is also urgent to increase the public service capacity for delivering specialised care to obese people. Furthermore, we need to increase health literacy as social media can at times spread inappropriate information about these obesity treatments. Education is key.

1.5 million Portuguese people have diabetes and that does not include the others indirectly impacted as family and carers. We have to rethink our approach and see obesity as a chronic disease that leads to diabetes, heart disease and even cancer and another 200 different diseases. It must not only be prevented but treated as well.

Is there a stigma around obesity in Portugal?

There is a strong stigma around it and this might lead to treatments being overlooked, assuming that people are just eating too much, and it is therefore a behavioural disease Obesity is a complex disease caused by many genetic, hormonal and psychological factors. People do need to change their behaviour, but medical treatments should be a part of their care and there should be a complete integrated health plan, not just one or the other.

This idea that environment is the main cause and obesity is the patient's fault can also be present in medical professionals. For example, at a seminar I did I used a study on adopted children. I asked practitioners whether the weight correlation of an adopted child at an adult age was more due to the biological parents or the adopting parents. Most answered that it is due to the adopting parents, as we have been taught that the environment is the key factor in obesity, but it is actually the biological parents. It was surprising for most of them that around 70 percent of our weight is controlled by genetics, as factors like appetite are part of that.

Portugal does have a clear problem of growing diabetes prevalence and the system needs to be developed, improving not just direct treatment but actions such as screening, to increase diagnosis and monitoring. We believe this should start in primary healthcare centres where improvements in diabetes strategies are essential.. These issues may increase further as the public national healthcare service faces a resource crisis. 40 percent of people with diabetes in Portugal are undiagnosed and these people eventually need to be treated once the condition bubbles to the surface. This fight for better treatment and overall care is something that the APDP has always been working for.

How do you see the outlook for the future? With so much to tackle, does it look positive?

Yes, because we have the resources in place. We have the information and the medical tools such as drug and treatment centres. If we put the government's work together with the experts that know the disease, then we are able to design a strategy that will save money in the long run, and this is to key the long-term sustainability of the healthcare system and the treatment of diabetes.

We have innovation and technology, and promoting therapies such as insulin pumps, or new drugs are short-term expenses for long term savings, something policy-makers must factor in to the decision-making process for reimbursement. I believe if we improve the management of our resources, we have everything to create a better future for patients and our society. Science is doing its part in bringing amazing developments forward. We need to work on creating a world where politics follow science and pursue people's well-being.

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