

## a) MANAGING YOUR LIFESTYLE

*"I have had Addison's for twelve years and have not had a crisis needing medical assistance since my diagnosis. I have raised seven children, run a motor vehicle repair business and drive extensively. I am 55 years old, very active. Like many others I have few side effects and am happy with my quality of life."*

**JAMES**

*"My body cannot be normal, but I do pretty well. Our limitations really are few. I guess we just need to learn at what point we should go on or stop to give our bodies a break?"*

**SANDRA**

*"I have had Addison's for 15 years and have never had a crisis. I have had a full-time job, raised three children alone when my husband died 16 years ago, still play volleyball and golf, and just feel like I keep a fairly normal schedule for a 50 year old!"*

**ROSEANNA**

Individuals with Addison's disease can expect to have a normal life span, provided they manage their daily medication sensibly. Addisonians can bring up a family on their own, hold down a demanding job, run marathons or even become the President of the United States.

That is not to say that life as an Addisonian will always feel 'normal'. Most individuals find they have to become skilled at managing the fatigue that accompanies the condition. In the last UK survey of Addisonians (1996/7), around 40% of respondents said they had ongoing difficulties with fatigue and a lack of energy. There is more information on managing fatigue in section 3: *Medication* and in section 4: *Common concerns*.

A number of people find they develop related auto-immune conditions such as diabetes or hypothyroidism, requiring extra healthcare management. There is more information on related autoimmune conditions in section 2: *The Causes of Addison's*.

Addisonians must always be aware of their own health and ready to increase their dosage if they get sick or are seriously injured. A North American survey (1997) found that three-quarters of respondents had received emergency treatment at a hospital for their Addison's disease at some point, while around 15% had had to use their emergency injection kit at home. There is more information on what to do if you are seriously ill in section 10: *Crisis management*.

A few individuals are less lucky and find that their health never recovers sufficiently to allow them to return to full-time work after diagnosis. Sometimes this is because they experienced serious damage to their health (such as a stroke) brought

# 1 HOW 'NORMAL' CAN LIFE BE WITH ADDISON'S DISEASE?

about by a delayed diagnosis. Sometimes it is because they have multiple health conditions, which include adrenal failure. So not everyone can run marathons, just as not all of us could become President.

Most of us, however, continue to lead busy and rewarding lives, with the support of our family, friends and medical professionals. And if you do want to run a marathon, there is more information in section 6: *Exercise*.

*"I have had Addison's for 20 years, and also hypothyroidism. I have also had diabetes for 40 years. I do work full time, and raised two girls, now 19 and 21. I was so glad to read about the experiences of others and discover that I really have an excuse for fatigue - not just lazy. My doctor never mentioned the exhaustion. I also get joint and back pain. Never incapacitating - just frustrating. But I do take good care of myself and have a wonderful doctor."*

**TRISH**

*"I work 9 to 5 and I have two boys. When I feel bad I feel exhausted and aching and can't get on with my life. People don't always feel great despite the medication."*

**GAIL**

## b) YOU AND YOUR DOCTORS

As an Addisonian, you are responsible for day-to-day management of your own health. You must take your daily medication at the right times and monitor your general health for any signs of serious illness where your medication might need increasing. Serious illnesses requiring extra medication are discussed in section 10 of this manual: *Crisis management*.

Most Addisonians are supported in their health management by two medical professionals: their General Practitioner and their endocrinologist.

In the UK, your General Practitioner (GP) is usually responsible for prescribing your current medication and for checking your general health status with you - including any problems unrelated to your Addison's.

In the UK, your GP will be able to authorise a Medical Exemption Certificate for you, allowing you to receive all prescription medication free of NHS charges, so please remember to ask them for this.

Your endocrinologist is generally responsible for reviewing your medication requirements and checking for any changes in your endocrine health. They will usually check for signs that your steroid medication may need adjusting up or down. Some Addisonians do also develop related autoimmune conditions, such as hypothyroidism or diabetes. Your endocrinologist will usually check for any signs of these. In the UK, most endocrinologists prefer to see their Addisonian patients every six to twelve months.

So, being a successful Addisonian means being a good communicator, as there are two medical professionals to keep informed about any important changes in your health.

Some Addisonians find it helps to keep a written record of their health status when there are important health issues they want to review with their GP or endocrinologist. At such times, a medical 'diary' can be a useful guide for your doctor, providing more specific information than you can recall in a general conversation. You will probably want to record the timing and amount of medication you take, your level of energy/fatigue and any other important health factors or changes.

*"My GP and I work well as a team and he also works well with my endocrinologist. My GP has admitted honestly that he does not know enough about the disease to care for me on his own."*

**SANDRA**

*"I see my endocrinologist every six months and it is amazing the changes that can happen even in that short time."*

**JOAN**

*"My endocrinologist is great. I have kept a journal in the past with symptoms matched to activities including blood pressure. The doctor used this to help match trends in relation to medication. A journal makes your information more accurate and credible. And you must educate yourself as much as possible."*

**ALAN**