

Information for individuals with adrenal incidentalomas



This patient leaflet is based on the European Society of Endocrinology Clinical Guideline on the management of adrenal incidentalomas in collaboration with the European Network for the Study of Adrenal Tumors, written by an expert pan-European Endocrine team. The aim of this guideline is to help clinicians managing patients who have an adrenal incidentaloma, and is published in the *European Journal of Endocrinology* (2023) 189: G1-G42. The information in this leaflet is not intended to replace your doctor's advice.

Background

You are recently diagnosed as having an adrenal incidentaloma. The adrenal glands are small, pyramidal shaped organs sitting on top of the kidneys (see Figure 1), that produce a variety of hormones. An adrenal incidentaloma is a mass (tumour) in these adrenal glands, incidentally found on radiological imaging which was originally performed for another reason than searching for adrenal disease (for instance, a CT scan of the abdomen, performed to look for appendicitis or causes of back pain). About 2% of adults have an adrenal incidentaloma, increasing to 10% in the elderly, which does not cause relevant health issues in the majority of cases. This patient leaflet is specifically designed to inform you how an adrenal incidentaloma is evaluated and managed based on the current guideline.

Evaluation

Once an adrenal incidentaloma is found, you will be referred to a hormone specialist (endocrinologist), to determine if:

1. The mass is producing any hormones

The adrenal glands produce a variety of hormones, such as adrenaline, aldosterone, and cortisol. These hormones are involved in several important processes in your body, such as regulation of blood pressure, metabolism and the immune system, and can also affect your mental health. To assess if the adrenal incidentaloma overproduces one (or more) of these hormones, your doctor will search for any signs or symptoms of hormonal overproduction and perform blood as well as urine tests if required.

2. The mass is benign or malignant

Fortunately, over 90% of adrenal incidentalomas are benign (meaning,



they are not cancerous). The most reliable first-line imaging method to assess if a mass is benign or malignant is a computed tomography (CT) scan without use of contrast media, which is reviewed by a radiologist. A CT scan combines a series of X-ray images taken from different angles around your body to produce “slices”. Other imaging modalities which can be used are MRI scan (using magnetic fields to make images of your body) or PET scan (using a radioactive drug (tracer)

to show both normal and abnormal metabolic activity).

Management

The result of imaging and blood and/or urine tests will usually guide the management of an adrenal incidentaloma. When the adrenal incidentaloma appears to be benign and not producing an excess of hormones, no further investigation or follow-up is needed. In the event the adrenal incidentaloma is producing excess hormone or showing some unusual or concerning features, a discussion by the multidisciplinary team (MDT) is usually needed to agree on the most appropriate approach to deal with the condition. An MDT usually consists of several

experts in adrenal tumours, such as an endocrinologist, surgeon, radiologist and specialist nurse. When there is evidence of overproduction of hormones or the mass appears to be malignant, surgical removal of the adrenal gland containing the incidentaloma (called an adrenalectomy) is usually the preferred treatment. Whether or not you will undergo surgery may also be influenced by other individual factors, such as your physical condition or age.

In some cases, a “wait-and-see policy” may be advised: you will need follow-up with your endocrinology team with repeat imaging and/or blood/urine tests. Further management will depend on the results of repeated testing.

Q & A

Q1: I have incidentalomas in both adrenal glands, or multiple incidentalomas in one adrenal gland; does the information in this leaflet apply to me?

A1: Yes, you will undergo the same evaluation of imaging and blood and/or urine tests. However, since the underlying causes may be slightly different from those who have a single, one-sided adrenal incidentaloma, your doctor may consider some additional tests.

Q2: If no surgery is performed, is it helpful/necessary to perform a biopsy to secure the correct diagnosis?

A2: No, a biopsy generally has no role in evaluation of an adrenal mass. It will only be considered under special circumstances, for instance when malignant disease outside of the adrenals is already present, or when there is suspicion of an infectious disease.

Q3: My adrenal incidentaloma causes ‘mild autonomous cortisol secretion’, what does this mean?

A3: Cortisol is one of the hormones which can be overproduced by an adrenal incidentaloma. When cortisol overproduction is evident and accompanied by typical features like fat accumulation in the abdominal area, easy bruising or muscle weakness, this is called Cushing’s syndrome. When such features are absent, this is called ‘mild autonomous cortisol secretion’. This (mild) overproduction of cortisol can have undesirable effects such as hypertension, type 2 diabetes or bone fragility. Your doctor will carefully examine you for these undesirable effects and if present, discuss appropriate treatment options.

Q4: My adrenal mass was detected during an evaluation due to a malignant disease. Does this mean that my adrenal mass is a metastasis of this other tumour?

A4: No, that doesn’t have to be the case – the risk is, amongst others, dependent on the type of underlying malignant disease. If the mass appears benign on a CT scan without intravenous contrast media, a metastasis is unlikely and no further specific imaging of the adrenals is needed. In other cases, additional investigations like a PET scan or biopsy may be considered. In all cases, you and your doctor will discuss which (hormonal) evaluation and management options will fit you best, based on individual factors like the stage of the underlying malignancy and quality of life.

Q5: Where can I get more information and support?

A5: You can find more information through the following website:
www.ese-hormones.org/for-patients/patient-advocacy-groups



T: +44 (0)1454 642247

E: info@euro-endo.org

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