MIDDLESBROUGH COUNCIL

SCRUTINY REPORT

HEALTH SCRUTINY PANEL

10 September 2019

Ehlers-Danlos Syndrome (EDS)

SUMMARY

Ehlers-Danlos syndromes (EDS) are a group of rare inherited conditions that affect connective tissue. Connective tissues provide support in skin, tendons, ligaments, blood vessels, internal organs and bones.

Locally, diagnosis and support for people experiencing EDS is commissioned by the Clinical Commissioning Group (CCG). Suspicion of EDS would normally be made by the GP who would then refer to an appropriate specialist service for further management if required dependent on the type of EDS. E.g. rheumatologist, genetic service.

People with EDS also benefit from support from a number of different healthcare professionals to which the GP or Consultant is able to refer - E.g. physiotherapist, occupational therapist – however there is not a single defined route in place for EDS patients to take due to the complexity and variation of patients presenting with EDS symptoms.

INTRODUCTION

Following receipt of correspondence from a representative of Ehlers-Danlos Teesside, the Health Scrutiny Panel requested for a discussion with commissioners to help understand the support available locally for people who are diagnosed with Ehlers-Danlos Syndrome/ Hypermobility Spectrum Disorders. Treatment and care for people diagnosed with EDS is commissioned by the Clinical Commissioning Group (CCG).

This report summarises the evidence available on EDS and the current pathways of care that are available.

EVIDENCE / DISCUSSION

Ehlers-Danlos syndromes (EDS) are a group of rare inherited conditions that affect connective tissue. Connective tissues provide support in skin, tendons, ligaments, blood vessels, internal organs and bones.

There are several types of EDS that may share some symptoms.

These include:

- an increased range of joint movement (joint hypermobility)
- stretchy skin
- fragile skin that breaks or bruises easily

In total there are 13 types of EDS, most of which are very rare. Hypermobile EDS (hEDS) is the most common type. Other types of EDS include classical EDS, vascular EDS and kyphoscoliotic EDS. The EDS Support UK website has more information about the different types of EDS.

The different types of EDS are caused by faults in certain genes that make connective tissue weaker. Depending on the type of EDS, the faulty gene may have been inherited from 1 parent or both parents. Sometimes the faulty gene is not inherited, but occurs in the person for the first time.

EDS can affect people in different ways. For some, the condition is relatively mild, while for others their symptoms can be disabling. Some of the rare, severe types can be life threatening.

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People with EDS also benefit from support from a number of different healthcare professionals to which the GP or Consultant is able to refer - E.g. physiotherapist, occupational therapist – however there is not a single defined route in place for EDS patients to take due to the complexity and variation of patients presenting with EDS symptoms. Many hypermobile patients will however be managed, at least for the majority of their lives, solely within Primary Care.

CONCLUSIONS

Locally, diagnosis and support for people experiencing EDS is commissioned by the Clinical Commissioning Group. Patients who present to their GP with EDS would present with multiple symptoms which make diagnosis complex. Suspicion of EDS would normally be made by the GP who would then refer to an appropriate specialist service for further management if required dependent on the type of EDS, however, many hypermobile patients will be managed, at least for the majority of their lives, solely within Primary Care.