Adiposis dolorosa

Adiposis dolorosa is a condition characterized by painful folds of fatty (adipose) tissue or the growth of multiple noncancerous (benign) fatty tumors called lipomas. This condition occurs most often in women who are overweight or obese, and signs and symptoms typically appear between ages 35 and 50.

In people with adiposis dolorosa, abnormal fatty tissue or lipomas can occur anywhere on the body but are most often found on the torso, buttocks, and upper parts of the arms and legs. Lipomas usually feel like firm bumps (nodules) under the skin. The growths cause burning or aching that can be severe, particularly if they are pressing on a nearby nerve. In some people, the pain comes and goes, while in others it is continuous. Movement or pressure on adipose tissue or lipomas can make the pain worse. In some cases, lipomas can impair normal movement.

Other signs and symptoms that have been reported to occur with adiposis dolorosa include easy bruising, digestive problems, a rapid heartbeat (tachycardia), general weakness and tiredness (fatigue), sleep problems, depression, irritability, confusion, migraine headaches, recurrent seizures (epilepsy), and a progressive decline in memory and intellectual function (dementia). These problems do not occur in everyone with adiposis dolorosa, and it is unclear whether they are directly related to the condition.

Frequency

Adiposis dolorosa is a rare condition whose prevalence is unknown. For reasons that are unclear, it occurs up to 30 times more often in women than in men.

Causes

The cause of adiposis dolorosa is unknown. The condition is thought to have a genetic component because a few families with multiple affected family members have been reported. However, no associated genes have been identified.

Several other possible causes of adiposis dolorosa have been suggested, although none have been confirmed. They include the use of medications called corticosteroids, dysfunction of the endocrine system (which produces hormones), or changes in the deposition and breakdown of fat (adipose tissue metabolism). Researchers have also suggested that adiposis dolorosa could be an autoimmune disorder, which occurs when the immune system malfunctions and attacks the body's own tissues and organs. However, there is no firm evidence that the condition is related to abnormal inflammation or other immune system malfunction.
It is unknown why adiposis dolorosa usually occurs in people who are overweight or obese, or why the signs and symptoms do not appear until mid-adulthood.

Inheritance Pattern
Most cases of adiposis dolorosa are sporadic, which means they occur in people with no history of the disorder in their family.

A small number of familial cases of adiposis dolorosa have been reported. When the condition runs in families, it appears to have an autosomal dominant pattern of inheritance because affected individuals inherit the condition from one affected parent. This pattern of inheritance suggests that one copy of an altered gene in each cell is sufficient to cause the disorder.

Other Names for This Condition
• adiposalgia
• adipose tissue rheumatism
• Anders syndrome
• Dercum disease
• Dercum-Vitaut syndrome
• Dercum's disease
• lipomatosis dolorosa
• morbus Dercum

Diagnosis & Management

Genetic Testing Information
• What is genetic testing?
https://primer/testing/genetictesting
• Genetic Testing Registry: Lipomatosis dolorosa

Research Studies from ClinicalTrials.gov
• ClinicalTrials.gov
https://clinicaltrials.gov/ct2/results?cond=%22adiposis+dolorosa%22

Other Diagnosis and Management Resources
• Merck Manual Consumer Version: Lipomas
https://www.merckmanuals.com/home/skin-disorders/noncancerous-skin-growths/lipomas
Additional Information & Resources

Health Information from MedlinePlus

- Encyclopedia: Lipoma - Arm
  https://medlineplus.gov/ency/imagepages/1209.htm
- Health Topic: Benign Tumors
  https://medlineplus.gov/benigntumors.html

Genetic and Rare Diseases Information Center

- Adiposis dolorosa
  https://rarediseases.info.nih.gov/diseases/5750/adiposis-dolorosa

Additional NIH Resources

- National Human Genome Research Institute: Learning About Dercum Disease
  https://www.genome.gov/Genetic-Disorders/Dercum-Disease

Educational Resources

- Karen L. Herbst, Ph.D., M.D.
  http://www.lipomadoc.org/dercums-disease.html
- MalaCards: adiposis dolorosa
  https://www.malacards.org/card/adiposis_dolorosa
- Merck Manual Consumer Version: Lipomas
  https://www.merckmanuals.com/home/skin-disorders/noncancerous-skin-growths/lipomas
- Orphanet: Adiposis dolorosa
  https://www.orpha.net/consor/cgi-bin/OC_Exp.php?Lng=EN&Expert=36397

Patient Support and Advocacy Resources

- American Chronic Pain Association
  https://www.theacpa.org/
- National Organization for Rare Disorders (NORD)
  https://rarediseases.org/rare-diseases/dercums-disease/

Scientific Articles on PubMed

- PubMed
  https://www.ncbi.nlm.nih.gov/pubmed?term=%28%adiposis+dolorosa%5BTIAB%5D%29+OR+%28Dercum+disease%5BTIAB%5D%29+AND+english%5BLang%5D+AND+human%5Bmh%5D+AND+last%3B3600+days%22+AND+date%22+AND+5D
Catalog of Genes and Diseases from OMIM

- ADIPOSIS DOLOROSA
  http://omim.org/entry/103200

Medical Genetics Database from MedGen

- Lipomatosis dolorosa

Sources for This Summary

  Citation on PubMed: https://www.ncbi.nlm.nih.gov/pubmed/11148491

  Citation on PubMed: https://www.ncbi.nlm.nih.gov/pubmed/22759645
  Free article on PubMed Central: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3416699/

  Citation on PubMed: https://www.ncbi.nlm.nih.gov/pubmed/22546240
  Free article on PubMed Central: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3444313/

  Citation on PubMed: https://www.ncbi.nlm.nih.gov/pubmed/22301856
  Free article on PubMed Central: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4010336/

  Citation on PubMed: https://www.ncbi.nlm.nih.gov/pubmed/23809264

  Citation on PubMed: https://www.ncbi.nlm.nih.gov/pubmed/15891252

  Citation on PubMed: https://www.ncbi.nlm.nih.gov/pubmed/17504714

Reprinted from Genetics Home Reference:

Reviewed: February 2019
Published: June 25, 2019