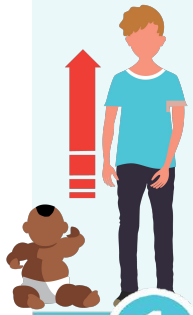
PL PATIENT JOURNEY – diagnosis, diet, acceptance

For many symptoms start just after birth

1 SYMPTOMS

- Symptoms may start just after birth and increase significantly in puberty
- Fat distribution appears normal at birth and in childhood. After puberty, the fat distribution, and lack of adipose tissue in extremities becomes more pronounced



- First symptoms often appear at puberty
- Abnormal distribution of body fat
- Variable hunger
- Possible diabetes

Skin tone can vary, common in Asian or dark skin patients

2 FIRST CONTACT WITH FAMILY DOCTOR/ PEDIATRICIAN

- Most likely the family doctor
- Years (30+) of symptoms and misdiagnosis can occur
- Mild symptoms can be ignored

Failure to control diet blamed on poor adherence?

They think its my fault. I feel so alone

Drops out of treatment pathway

Everything is about diagnosis, diet and acceptance

SUPPORT FROM PATIENT GROUPS

Support form patient advocacy groups is vital

3 REFERRAL

Referral to specialist, variety of possibilities, often diabetologist

Drops out of treatment pathway

4 1ST TO 3RD LINE MEDS

- Oral anti-diabetics
- Insulin
- Lipid-lowering therapies
- Exercise and diet, such as a low carb diet

METABOLIC SYNDROME

May be considered "under control"

5 Lipodystrophy patients live day to day with symptoms such as fatigue and brain fog.

Short cuts to treatment

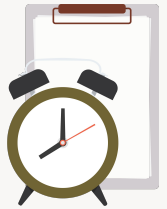
6 SUSPECTED DIAGNOSIS

- Insulin resistance
- NASH
- Cardio abnormalities
- Family history
- Many triggers

Drops out of treatment pathway

7 METABOLIC SYNDROME

- May be considered "under control"
- Need to catch patients early before damage



8 COMPLICATIONS

- Pancreatitis – accused of being a drug addict or alcoholic
- Liver/kidney damage
- Cardiomyopathy
- Infections
- Temperature control
- Pain as a result of loss of fat

Drops out of treatment pathway

9 DIAGNOSIS / SECOND-LINE SPECIALIST

May see:
- Dermatologist
- Cardiologist
- Nephrologist
- Hepatologist

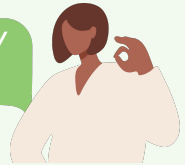
May refer on to Centre of Excellence

Great, I finally have a diagnosis but what does this mean now

10 LEPTIN REPLACEMENT THERAPY

- Myalept(a) treatment and help from dietician
- Managed by CofE

I'm not hungry all the time anymore



11 THE JOURNEY CONTINUES

- Living with the long-term consequences of partial lipodystrophy
- Patients will still look very different than the general population