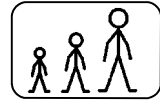


Version 17. 10/12

Neurofibromatosis Type 1

Review Guidelines



Annual Review Recommended

At time of diagnosis, or possible diagnosis, ALL patients should be seen in a genetics department. Those with significant complications will be followed up as appropriate through the nationally-funded Complex Nf1 Service. Annual review should be undertaken by a Community/District Paediatrician and GP throughout childhood, and by a GP in adulthood. Patients, paediatricians and GPs have telephone access to the NF Service in Genetic Medicine for NF-related concerns.

AGE	GENETICS APPOINTMENT	NF1 REVIEWS CARRIED OUT BY	VISION CHECKS
<6 & 50% risk	In first year and then at 2 and 5* ¹	Care coordinated by Genetics.	Symptom check at Nf1 review
<8 affected	Confirmation of diagnosis & assessment. Genetic counselling for family.	GP and Community/ District Paediatrician. Liaison with NF service for complex cases.	At least annual with paediatric ophthalmologist.
8 – 15 affected	On request		Annual with optician/orthoptist
16—18 affected	Appointment for counselling re: adult complications and genetics	Care coordinated by GP.	Symptom check at Nf1 review
>16 affected* ²	On request		

*¹If no café au lait spots by 5 years, NF1 can be excluded in the majority of NF1 families.

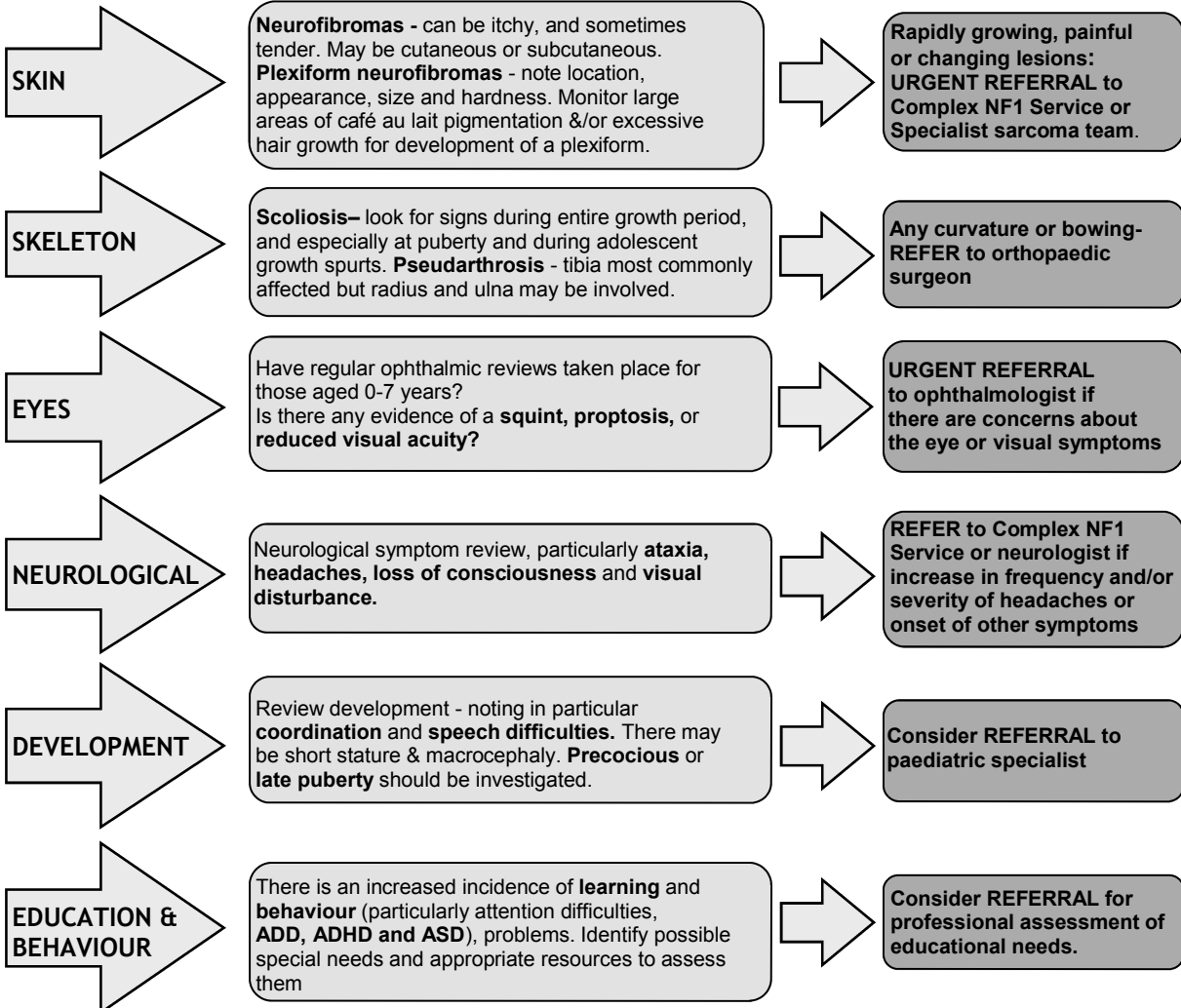
*²Women aged 40—50 should be referred for annual mammography as per 'moderate risk' NICE guidelines.

Review Checklist—Children (0—16)

Record **height, weight** and **head circumference**. Take **blood pressure** as soon as feasible. If raised, see the Adult Review Checklist (p.2) for info.

WHAT TO LOOK FOR

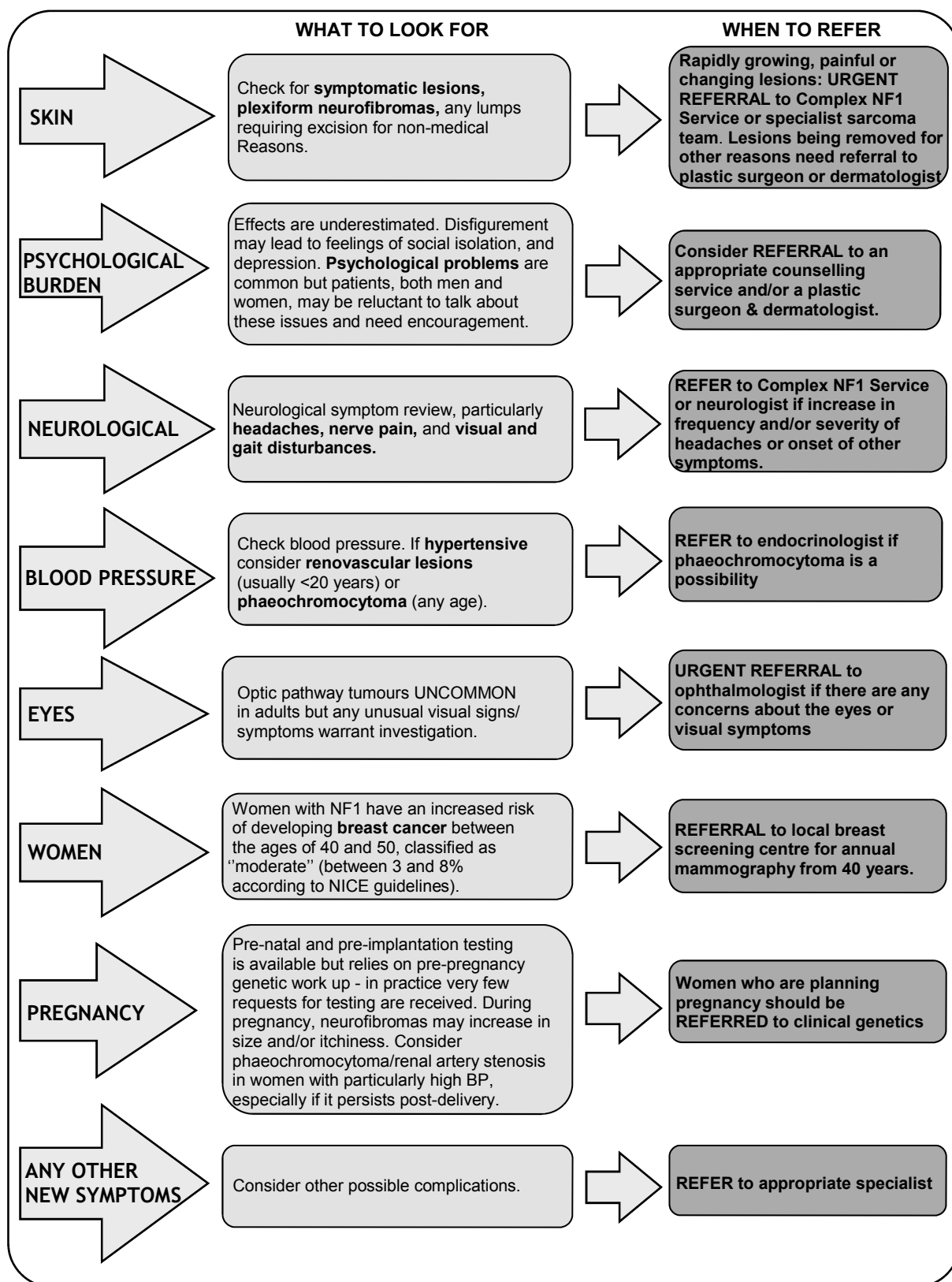
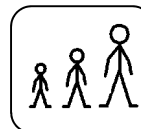
WHEN TO REFER



UNSURE? Do not hesitate to contact the NF1 team if you have any queries—contact details are at the bottom of p.2

Neurofibromatosis Type 1

Review Checklist—Adults (16+)



Complex Nf1 Service: Dr Huson (Secretary): 0161 276 5152
Nurse Specialist: 0161 701 2043

Central Manchester University Hospitals NHS Foundation Trust

Genetic Medicine, St Mary's Hospital, Manchester M13 9WL Tel: 0161 276 6506 www.mangen.co.uk

The Neuro Foundation, Tel: 020 8439 1234/1200 Email: info@nfauk.org Website: www.nfauk.org

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