

Newcastle Mitochondrial Centre

At a glance guidelines:

**Lower urinary Tract
Dysfunction in Adult
Mitochondrial Disease**

For full guideline visit:

<http://www.newcastle-mitochondria.com/service/patient-care-guidelines/>

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There are many different forms of mitochondrial disease, varying greatly in their genetic basis, clinical presentation, progression and prognosis. We recommend referral to a specialist mitochondrial centre for appropriate counselling and guidance (www.mitochondrialncg.nhs.uk or see appendix for international centres).

Clinically relevant Lower Urinary Tract dysfunction may be a prominent feature of some forms of mitochondrial disease. These patients are potentially at risk of long-term complications of bladder dysfunction including chronic urinary retention with its inherent increased risk of recurrent infection and renal impairment. We therefore recommend the following:

1. The diagnosis of lower urinary tract dysfunction is best made by a Specialist Urologist.
2. Initial assessment should be made through directed history taking at the time of diagnosis
3. Symptomatic assessment of lower urinary tract symptoms should be carried out using a combination approach:
 - i. Bladder voiding efficiency (BVE) measurement using void volume (VV) and post void residual (PVR) volumes calculated using the following formula:
$$BVE = [VV/(VV+PVR)] * 100$$
 - ii. ICIQ-LUTS questionnaire severity score; a gender specific validated international standard questionnaire used to subjectively evaluate lower

urinary tract symptoms in terms of their severity and bother. This assesses four symptom domains: storage, voiding, incontinence, and post-micturition (available from <http://www.icig.net/>).

- iii. Completion of a three-day bladder diary used to determine median urinary frequency, functional bladder capacity, voided volume, and episodes of urinary leakage.
4. Patients with ICIQ-LUTS score of >60%, BEE <70%, or bladder diary suggestive of high urinary frequency, low functional bladder capacity or frequent episodes of urinary incontinence should be offered referral to Urology services for urodynamic testing.
 5. Further assessment should be made at regular intervals (eg. annual review and opportunities arising from unrelated GP visits), or if clinical status changes with development of symptoms suggestive of gastro-intestinal involvement.

The bladder diary is designed for us to understand your bladder habits and will prove helpful in understanding how these habits relate to any bladder-related symptoms in mitochondrial disorders.

Instructions

In the diary, please tick (✓) each time you go to the toilet to pass urine and, if possible, the amount (volume) you pass each time.

The easiest way to do this is to place a household measuring jug in the toilet (provided to you by the research team) and pass urine directly into this jug. Make note of the amount in the bladder diary.



Please note that you may discard your urine sample after measuring the amount.

Also make a note of any times that you leak urine. You can record severity of any leakage of urine as follows:
 + damp, ++ wet, +++ soaking.

An example is shown on the right.

When you go to bed, put a line on the chart next to the time, so we can tell how many times you have to get up to pass urine. Also put a line next to the time you get up for the day.

Please try to fill in three complete days and nights to give us enough information about your bladder habits.

EXAMPLE DIARY ENTRY

TIME	DAY ONE		
	DATE: <u>11 / 01 / 2017</u>		
	Tick when you go to the toilet	Volume of urine passed (if known)	Leakage of urine (if any)
12 (midnight)			
1am			
2am	✓	200mls	
3am			
4am			
5am			
6am			++
7am	✓	300mls	
8am			
9am			
10am			
11am			
12 (noon)	✓	250mls	
1pm			+
2pm			
3pm			
4pm			
5pm			
6pm	✓	50mls	+++
7pm			
8pm			
9pm	✓	100mls	
10pm			
11pm			

