

# National Collaborative Study for Lysosomal Storage Disorders – Service use and costs to child patients and their families

(questions for completion by Parents or the Main Carers of children)

The collaborating specialists from LSD treatment centres, and the relevant patient Associations and Societies, are keen to understand the broader impact of LSDs on children's lives. The following questions therefore mainly ask what health care and other services your child has used because of their condition or other health problems. There are also some optional questions at the end which ask about your household situation, and employment status which would also be useful for us to know about.

1. In the last 12 months, has your child had any short-term absences from school/nursery because of their health problems?

Yes  
No

*If yes:*

Approximately how many days in the past 12 months has your child taken off school because of their health problems? \_\_\_\_\_ days

2. In the last 12 months, has your child had any contact with **hospital services**?

Yes

(e.g. inpatient admissions, outpatient or emergency attendances)

No

**If yes:**

a. **Inpatient care:** Reason for hospital stay 1 \_\_\_\_\_

In which hospital? \_\_\_\_\_

No. of days in hospital for this stay \_\_\_\_\_

Reason for hospital stay 2 \_\_\_\_\_

In which hospital? \_\_\_\_\_

No. of days in hospital for this stay \_\_\_\_\_

Reason for hospital stay 3 \_\_\_\_\_

In which hospital? \_\_\_\_\_

No. of days in hospital for this stay \_\_\_\_\_

*(For the next questions 'reason for attendance' means a specific health problem. If your child has received outpatient care for more than one health problem please detail these separately as the first, second, third (etc.) reasons for attendance.)*

b. **Hospital Outpatient care:**

Reason for attendance (1) \_\_\_\_\_

No. of attendances (for this reason) in last 12 months \_\_\_\_\_

Reason for attendance (2) \_\_\_\_\_

No. of attendances (for this reason) in last 12 months \_\_\_\_\_

Reason for attendance (3) \_\_\_\_\_

No. of attendances (for this reason) in last 12 months \_\_\_\_\_

c. **Day hospital:** Reason for attendance (1) \_\_\_\_\_

No. of attendances (for this reason) in last 12 months \_\_\_\_\_

Reason for attendance (2) \_\_\_\_\_

No. of attendances (for this reason) in last 12 months \_\_\_\_\_

Reason for attendance (3) \_\_\_\_\_

No. of attendances (for this reason) in last 12 months \_\_\_\_\_

d. **A and E:** Reason for attendance (1) \_\_\_\_\_

No. of attendances (for this reason) in last 12 months \_\_\_\_\_

Reason for attendance (2) \_\_\_\_\_

No. of attendances (for this reason) in last 12 months \_\_\_\_\_

Reason for attendance (3) \_\_\_\_\_

No. of attendances (for this reason) in last 12 months \_\_\_\_\_

3. Please give details of any of the following services that your child has used *outside of hospital* in the last 12 months. This should include all telephone contact.

<i>Service</i>	<i>Was the service used?</i>	<i>Number of contacts in last 12 months</i>	<i>Typical duration of each contact (minutes)</i>	<i>Was the contact at home?</i>	<i>If service was paid for privately, give amount paid per attendance/use</i>
General Practitioner	No/Yes			No/Yes	
Practice nurse (at the GP clinic)	No/Yes			No/Yes	
District Nurse	No/Yes			No/Yes	
Community mental health nurse	No/Yes			No/Yes	
Other nurse or health visitor	No/Yes			No/Yes	
Counsellor	No/Yes			No/Yes	
Other therapist	No/Yes			No/Yes	
<i>Type</i> _____					
'Alternative' medicine or therapy	No/Yes			No/Yes	
<i>Specify</i> _____					
Psychologist	No/Yes			No/Yes	
Psychiatrist (community or primary care based)	No/Yes			No/Yes	
Other community based doctor	No/Yes			No/Yes	
<i>Specify</i> _____					
Occupational therapist	No/Yes			No/Yes	
Social worker	No/Yes			No/Yes	
Home help / home care worker	No/Yes			No/Yes	
Care attendant	No/Yes			No/Yes	
Community support worker	No/Yes			No/Yes	
Housing worker	No/Yes			No/Yes	
Voluntary worker (including priest etc.)	No/Yes			No/Yes	
<i>Specify</i> _____					
Day centre/drop-in/social club	No/Yes			No/Yes	
<i>Name</i> _____					
Self-help group	No/Yes			No/Yes	
<i>Name</i> _____					

4. In the last 12 months, have you received help from **friends or relatives** on any of the following tasks, as a consequence of your child's health problems?

<i>Type of help</i>	<i>Was help received?</i>	<i>Helper's relationship to you (see key below)*</i>	<i>Average number of hours help per week</i>
Child Care <i>(circle 'No' if interviewee has no children)</i>	No/Yes		
Personal care <i>(e.g. washing, dressing etc.)</i>	No/Yes		
Help in/ around the house <i>(e.g., cooking, cleaning etc.)</i>	No/Yes		
Help outside the home <i>(e.g., shopping, transport etc.)</i>	No/Yes		
Other (please state):	No/Yes		
Other (please state):	No/Yes		

\* Key: 1 = Mother; 2 = Father; 3 = Brother/ Sister; 4 = Other Relative; 5 = Friend; 6 = Other (please specify)

5. For each of the following types of health service use by your child (over the last 12 months), what was the approximate cost to you and/or your family for travel, parking, and accommodation?

5a. for each **hospital inpatient** stay: Transport fares: Train £\_\_\_\_\_ Bus £\_\_\_\_\_ Taxi £\_\_\_\_\_

Mileage by car? \_\_\_\_\_miles (whole trip)

Parking costs £\_\_\_\_\_

Accommodation (eg. Hotel/B&B) costs £\_\_\_\_\_

5b. for each **day hospital** visit: Transport fares: Train £\_\_\_\_\_ Bus £\_\_\_\_\_ Taxi £\_\_\_\_\_

Mileage by car? \_\_\_\_\_miles (whole trip)

Parking costs £\_\_\_\_\_

Accommodation (eg. Hotel/B&B) costs £\_\_\_\_\_

5c. for each **A & E attendance**: Transport fares: Train £\_\_\_\_\_ Bus £\_\_\_\_\_ Taxi £\_\_\_\_\_

Mileage by car? \_\_\_\_\_miles (whole trip)

Parking costs £\_\_\_\_\_

5d. for each **GP visit**: Transport fares: Train £\_\_\_\_\_ Bus £\_\_\_\_\_ Taxi £\_\_\_\_\_

Mileage by car? \_\_\_\_\_miles (whole trip)

Parking costs £\_\_\_\_\_

6. Have you/they used any other services, or incurred any other specific costs as a result of your child's illness over the past 12 months? If so, please give further details:

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*Some further OPTIONAL questions about your household and your employment status*

11. Who does your child usually live with?
- |           |                          |   |
|-----------|--------------------------|---|
|           | Both parents             | 7 |
|           | One parent               | 8 |
|           | Other carer(s)           | 9 |
| <b>OR</b> | I do not wish to comment |   |
12. Employment status
- |           |   |    |
|-----------|---|----|
|           | Paid employment - full-time                     | 1  |
|           | Paid employment – part-time                     | 2  |
|           | Voluntary work (unpaid)                         | 3  |
|           | Sheltered work                                  | 4  |
|           | Registered as unemployed but available for work | 5  |
|           | Unemployed due to illness                       | 6  |
|           | Retired   | 7  |
|           | Student   | 8  |
|           | Housewife/husband                               | 9  |
|           | Other   | 10 |
| <b>OR</b> | I do not wish to comment                        |    |
13. Please give details of any way in which you think your child's health problems have or may have constrained their opportunities (such as, choice of school; school attendance; ability to participate in social activities)

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Is there any other information about how your child's condition impacts on you or your family's situation, or comments on this questionnaire, which you would like to tell us about?

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Thank you for taking the time to answer these questions.

Your answers are very important in building a complete picture of how the different lysosomal storage disorders affect people, their families and the use of NHS services