



CHRONIC NEURODISABILITY STUDY

National Confidential Enquiry into Patient Outcome and Death (NCEPOD)

ORGANISATIONAL QUESTIONNAIRE

4. COMMUNITY PAEDIATRICS

Name of Trust/Board/Organisation: _____

CONFIDENTIAL

Who completed this questionnaire?

Name: _____

Position: _____

What is this study about?

This study explores the quality of health care for children and young people aged 0-25 with chronic neurodisability across the UK.

Aims:

To identify remediable factors in the quality of care provided children and young people chronic disabling conditions, the cerebral palsies.

To examine the interface between different care settings

To examine the transition of care

Who should complete this form?

The clinician/s with the best overall knowledge of community/disability healthcare that includes children and young people with cerebral palsies delivered by this organisation. Please link with colleagues as need be to inform the most accurate possible response.

To ensure confidentiality of the data, completed questionnaire must be returned directly to NCEPOD in the SAE provided.

How to complete the form:

Information will be collected using two methods; box cross and free text, where your opinion will be requested.

This form will be electronically scanned. Please use a black or blue pen. Please complete all questions with either block capitals or a bold cross inside the boxes provided e.g.

Following crisis or emergency referral, are there any standards set for assessment from time of referral?

Yes No

If you make a mistake, please "black-out" the incorrect box and re-enter the correct information, e.g.

Yes No

Unless indicated, please mark only one box per question.

Questions or help?

A list of definitions is provided on pages 2 of the questionnaire.

If you have any queries about this study or this questionnaire, please contact

cp@ncepod.org.uk

Or telephone: 020 7251 9060

Thank you for taking the time to complete this questionnaire. The findings of the study will be published in late 2017.

ORGANISATIONAL ID



7 9 5 7 4 4 6 3 1 0 0 5 3

DEFINITIONS

Reasonable adjustments	“Employers and organisations such as hospitals, care homes and GP surgeries must take steps to remove the barriers people face because of their disabilities” (CQC, 2015. http://www.cqc.org.uk/content/glossary-terms-used-guidance-providers-and-managers#)
Interagency strategic partnership arrangements	A formal mechanism for considering the strategic needs of the local population of disabled children and young people
Out of hours	18:00 – 07:59 Monday to Friday and all day Saturday and Sunday
Accessibility of services	To be fully accessible, a service must have: <ul style="list-style-type: none"> o Accessible parking for the disabled o Ramped access o Doors wide enough for wheelchair access o Accessible toilets o Changing place for children and young people of all ages with cerebral palsies who are incontinent and need to be changed o Hoists o Accessible, height adjustable beds and examination couches o Appropriate scales e.g. wheelchair scales, hoist scales o Reasonable adjustments made to accommodate the specific needs of the disabled person
Individualised Emergency Health Care/Personal Resuscitation plan	Plan agreed with the lead clinician, that documents what has been discussed and agreed and with whom, about appropriate levels of intervention for the child/young person (e.g. any advance statements, advance decisions to refuse treatment, do not attempt cardiopulmonary resuscitation decisions, variations from advanced life support guidelines, treatment or intervention limitations.
Capacity	As defined in the Mental Capacity Act 2005 (applies in E&W) and equivalent legislation in Scotland and NI See https://www.disabilitymatters.org.uk/course/view.php?id=62
Best-interests decision-making	See https://www.disabilitymatters.org.uk/course/view.php?id=63
Gross Motor Function Classification System (GMFCS)	See: https://www.canchild.ca/en/resources/42-gross-motor-function-classification-system-expanded-revised-gmfcs-e-r



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A. THE TRUST/ORGANISATION/PROVIDER/HEALTH BOARD

- 1a. Up to what age does this organisation provide paediatric community/ specialist disability care? (What does this organisation define as a child?) Years
- 1b. What does this organisation define as an adolescent? (age range in years)
-

Please complete the remainder of this questionnaire in relation to the care provided to CHILDREN AND ADOLESCENTS as defined by this organisation. For the remainder of this questionnaire children and adolescents will be referred to as children and young people.

B. POPULATION OVERVIEW, DATA AND STRATEGIC ISSUES

2. Is there a lead clinician or team for the care of disabled children and young people within this service? Yes No

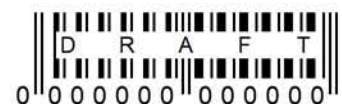
C. ACCESS TO SERVICES FOR CHILDREN AND YOUNG PEOPLE WITH CEREBRAL PALSIES

- 3a. Is there an agreed, written care pathway for assessment, diagnosis and management of children and young people with cerebral palsies who are seen in this service? Yes No

3b. Does this include:

	Yes	No
Hip surveillance	<input type="checkbox"/>	<input type="checkbox"/>
Magnetic Resonance Imaging of head and/or spine	<input type="checkbox"/>	<input type="checkbox"/>
Pain identification and management	<input type="checkbox"/>	<input type="checkbox"/>
Anthropometric measurement and monitoring of growth and nutrition	<input type="checkbox"/>	<input type="checkbox"/>
Spine monitoring and when to refer to spinal orthopaedic surgeon	<input type="checkbox"/>	<input type="checkbox"/>

- 3c. If yes to 3a, where is this pathway published so that referrers and parents know how to access the service? (Answers may be multiple)
- Local Offer (England) Organisation website Not published
- Written referral guidance for GPs, health visitors etc.
- Other (Please specify)



D. OPERATIONAL SERVICE DELIVERY MODEL FOR CLINICAL SERVICES

4. Does this community/specialist disability care service provide clinics for children and young people with cerebral palsy that are: (please tick all that apply)

- Non-specialist - seen as part of general community clinical caseload
- Specialist uni-disciplinary, i.e. each specialist sees the child or young people separately
- Multi-disciplinary for postural management (please specify which professionals are involved in the MDT clinics in the space below)
- Multi-disciplinary for feeding management (please specify which professionals are involved in the MDT clinics in the space below)
- Outreach clinics in special schools

Other (Please specify)

5. How do the various health professionals within this service work together in delivering healthcare for children and young people with cerebral palsies? (please tick all that apply)

- | | |
|---|---|
| <input type="checkbox"/> Regular meetings | <input type="checkbox"/> Ad hoc meetings focused on specific individuals |
| <input type="checkbox"/> Multidisciplinary clinics | <input type="checkbox"/> No meetings but communicate regularly by letter or email |
| <input type="checkbox"/> Co-location of professionals | <input type="checkbox"/> No regular arrangements for joint working |

Other (Please specify)

6. Please indicate how the following services are accessed for children and young people who are patients in the community? (Please tick all that apply)

	On-site	Off-site through a formal network	Off-site through an informal network	No access
Paediatrician with specialist expertise in neurodisability/cerebral palsies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatric neurologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatric gastroenterologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatric surgeon/general surgeon with an interest in children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatrician with specific interest in epilepsy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Orthopaedic surgeon with expertise in children and young people's cerebral palsies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatric pain specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



6. Continued

	On-site	Off-site through a formal network	Off-site through an informal network	No access
Orthopaedic surgeon with expertise in children and young people's cerebral palsies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Spinal orthopaedic surgeon with paediatric expertise	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ENT surgeons with paediatric expertise	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Audiology with paediatric expertise	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ophthalmology with paediatric expertise	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatric respiratory physician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatric physiotherapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatric dietician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatric occupational therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatric clinical psychology	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatric speech and language therapist - communication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatric speech and language therapist - dysphagia, feeding and swallowing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Children's specialist community nurse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Children and young people's learning disability nurse specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Children's epilepsy nurse specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatric continence specialist practitioner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Child and adolescent mental health service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Child and adolescent mental health service specifically for children and young people with learning disability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Specialist children and young people's dental services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychological support for parents/family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



E. SERVICES AND PROCEDURES

7a. Which of the following procedures/interventions can be accessed for children and young people with cerebral palsies seen in the community?

	On-site	Off-site through a formal network	Off-site through an informal network	No access
Magnetic resonance imaging without sedation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Magnetic resonance imaging with sedation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Magnetic resonance imaging under general anaesthetic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Standardised pelvic xray for hip surveillance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
pH studies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Botulinum toxin injections under sedation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gait analysis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7b. If MRI is undertaken, is this arranged for children and young people with suspected cerebral palsies:

Routinely Selectively depending on clinical assessment

(If MRI is selectively undertaken, please specify criteria)

7c. Is there specialist paediatric neuroradiological expertise available to interpret MRI findings (not necessarily onsite)?

Yes No

7d. If yes, is this available:

Routinely On an ad hoc basis

7e. What is the waiting list time for "routine" MRI from the paediatric outpatient department for disabled children and young people? (in weeks)

No sedation Weeks

Under sedation Weeks

Under general anaesthetic Weeks



F. ACCESSIBILITY

ACCESSIBILITY OF OUTPATIENT SERVICES FOR ALL CHILDREN AND YOUNG PEOPLE WITH CEREBRAL PALSIES INCLUDING WHEELCHAIR USERS WHO ARE TOTALLY DEPENDENT ON OTHERS FOR ALL CARE

8a. In general, across this outpatient service are there any problems with access to:

	Yes	No
Accessible parking for the disabled	<input type="checkbox"/>	<input type="checkbox"/>
Ramped access	<input type="checkbox"/>	<input type="checkbox"/>
Doors wide enough for wheelchair access	<input type="checkbox"/>	<input type="checkbox"/>
Accessible toilets	<input type="checkbox"/>	<input type="checkbox"/>
A changing place providing privacy for essential personal care	<input type="checkbox"/>	<input type="checkbox"/>
Accessible height adjustable beds and examination couches	<input type="checkbox"/>	<input type="checkbox"/>
Hoists	<input type="checkbox"/>	<input type="checkbox"/>
Appropriate scales (e.g. wheelchair scales, hoist scales)	<input type="checkbox"/>	<input type="checkbox"/>
Reasonable adjustments made to accommodate the specific needs of the disabled child or young person	<input type="checkbox"/>	<input type="checkbox"/>

8b. If yes to any of the above, please give details:

G. SYMPTOM MANAGEMENT

9a. For children and young people with cerebral palsies at GMFCS levels I and II (independently mobile without the need for devices) healthcare is most likely to be led by:

- | | | |
|---|---|--|
| <input type="checkbox"/> GP | <input type="checkbox"/> Community paediatrician | <input type="checkbox"/> General paediatrician |
| <input type="checkbox"/> Disability paediatrician | <input type="checkbox"/> Orthopaedic surgeon only | <input type="checkbox"/> Orthopaedic surgeon and paediatrician |
| <input type="checkbox"/> Other (Please specify) | | |



9b. For children and young people with cerebral palsies at GMFCS levels III and IV (dependent on devices or wheelchairs for mobility, but not completely dependent on other people, able to self-propel manually or in power chair) healthcare is most likely to be led by:

- GP Community paediatrician General paediatrician
 Disability paediatrician Orthopaedic surgeon only Orthopaedic surgeon and paediatrician
 Other (Please specify)

9c. For children and young people with cerebral palsies at GMFCS level V (completely dependent on other people to propel wheelchairs for mobility) healthcare is most likely to be led by:

- GP Community paediatrician General paediatrician
 Disability paediatrician Orthopaedic surgeon and paediatrician
 Other (Please specify)

10. Is there a policy of ALWAYS enquiring about the presence (or not) of pain at each consultation? Yes No

11a. In general, who is responsible for hip surveillance? (Tick all that apply)

- Physiotherapist GP Community paediatrician
 General paediatrician Disability paediatrician Orthopaedic surgeon
 Ad hoc hip surveillance No standardised hip surveillance in place

11b. In general, who is responsible for spine surveillance for those at GMFCS III-V? (Tick all that apply)

- Physiotherapist GP Community paediatrician
 General paediatrician Disability paediatrician Orthopaedic surgeon
 Ad hoc hip surveillance No standardised hip surveillance in place

12a. If a scoliosis or other spinal curvature is identified, is a referral made to the spinal orthopaedic surgeon? Yes No

12b. If YES, is this:

- Immediately on identification of the curvature
 When the clinician thinks the curvature may need surgical intervention
 Not referred to spinal orthopaedic surgeon, managed conservatively

13. Are evidence-based guidelines (e.g. NICE CG137/SIGN 143) followed for the assessment and management of patients with epilepsy? Yes No



G. SUPPORT SERVICES

14a. What FAMILY SUPPORT systems are available for children and young people with cerebral palsies who attend paediatric clinics? (Please tick all that apply)

	On-site	Off-site through a formal network	Off-site through an informal network	No access
Children's social work team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Parents information officer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Carer support groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clinical psychology	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Parent carer forum/council	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Young people's forum	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Young carer support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Short breaks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Advice on benefits and financial support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sibling support including psychology	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other (Please specify)

Children's social work team

14b. If a CHILDREN'S SOCIAL WORK TEAM is available, does this team support:

- All families with disabled children and young people routinely
- Only involved if there are safeguarding issues

14c. What are the thresholds for the involvement of the team? (Please specify)

Short breaks

15. Are short breaks available for all disabled children, young people and their families who need them?

Yes No



16. Other than a social worker, is there a family liaison officer/support worker/ carer's centre team for children and young people who are seen by this service? Yes No

School support

17. What SCHOOL SUPPORT systems are in place for children and young people with cerebral palsies seen by this service? (Please tick all that apply)

- Specialist teachers for children and young people with physical and medical needs
- Specialist teachers for children and young people with vision impairments
- Specialist teachers for children and young people with hearing impairments
- Specialist teachers/team for children and young people with autism spectrum disorders
- Educational psychology
- Other (Please specify)

18. Are you able to recommend accessible leisure opportunities that are available locally? Yes No

H. COMMUNICATION ISSUES

19. Whilst under this service, are children and young people given the opportunity to speak to health professionals without a parent present if they prefer to? Yes No
- 20a. Are "Right from the Start" (or equivalent) guidelines embedded in this community/disability service to inform communication about diagnosis? Yes No
- 20b. Has there been specific training in 'Right from the Start' (or equivalent) in this service? Yes No
21. Are parents given written information at the time of diagnosis? Yes No
22. Are parents provided with sources of information and support? (Please tick all that apply)
- Locally Nationally

Please specify

I. COMMUNICATION IN AN EMERGENCY

- 23a. Is there an agreed system in place for preparing written emergency health care plans (which may include personal resuscitation plans) for those with the most complex medical/surgical needs? Yes No
- 23b. How well is this system implemented in the regular care of severely disabled children and young people?
- Completely (all patients with complex needs have such a plan in place) Partially Not implemented



24. Are written communications, including Emergency Health Care Plans and 24 hour postural management plans, available in other languages or formats if required? Yes No
25. For children and young people seen in this service, is there access to a key worker/lead professional for families?
- Routinely available for disabled children/young people and families
- Only available for those with the most complex disabilities
- Only available for pre-school children

J. TRAINING

26. Is any training provided (either for specific procedures or broad areas of management) for children and young people seen by this community/disability service in aspects of self management? Yes No
27. Is any training provided for parent carers of disabled children and young people seen by this service in aspects of management, including technology dependencies (for example ventilator, gastrostomy tube, VP shunt)? Yes No
28. Does this service provide training for care workers locally in aspects of management of cerebral palsies? Yes No
- 29a. Does this service provide training for other professionals providing services for disabled children, young people and their families (e.g. doctors, therapists, teachers, social workers, health visitors, school staff, leisure providers etc)? Yes No
- 29b. If yes, does this training include any of the following?
- Disability training at induction Disability training embedded in regular training
- No disability-specific training Other (Please specify)

- 29c. Are disabled children, young people and/or families involved in delivering any of the above training? Yes No
- 29d. If yes to question 29c, please provide details.

K. TRANSITION TO ADULT SERVICES

- 30a. Does this organisation have clear policies in place to ensure continuity of patient care, including close handover between professionals, and familiarisation with case histories, at all interfaces and points of transitions of care? Yes No



30b. Does the recognised transition framework or policy specify the following elements? (Please tick all that apply)

- A designated specific care coordinator at transition?
- Clear written information including that of a key/lead contact within a particular agency?
- Clear information about emergency and out of hours access to advice if needed after transition?
- Regular and consistent age appropriate support at transition?

31. What arrangements are in place for young people under this service to support person-centred transition to adult services? (Please tick all that apply)

- Specialist transition team/Person-centred planners
- Specialist learning disability transition nurse/s
- Specialist disabled children's social work team to support transition
- No specific transition arrangements
- Other (Please specify)

32a. Within this organisation is transition to adult neurodisability services for young people based primarily on age? Yes No

32b. If yes, at what age does transition generally occur between paediatric neurodisability services and services for adults? (Please specify)

33. Is there a designated professional that leads on the planning of transition care between neurodisability services for young people and adults? Yes No

34. Does this organisation monitor how well the transition policy works? Yes No

35. Is there a policy for young people to be offered the opportunity to be seen separately from their parent/carer in this service? Yes No

36. To what services do young people with cerebral palsies transfer when leaving paediatric services, when ongoing secondary healthcare is needed? (Answers may be multiple)

- No services to transfer to
- Specific transfer arrangements with GP
- Neuro-rehabilitation specialist
- Other specialist physician/surgeon (please specify)

37. Are there MENTAL HEALTH services for young people with cerebral palsies in adult services:

- For those with a learning disability
- For those without a learning disability
- Both
- Unknown

38. Are there SOCIAL CARE services for young people with cerebral palsies in adult services: (Please tick all that apply)

- For those with a learning disability
- For those without a learning disability
- For those who are completely dependent on others for all of their care?
- Unknown



39. Are there services available to support young people with cerebral palsies with access to appropriate:
- | | | |
|-----------------|------------------------------|-----------------------------|
| Work experience | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Employment | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Training | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

L. DECISION-MAKING WITH CHILDREN AND YOUNG PEOPLE WITH CEREBRAL PALSIES

- 40a. Is capacity routinely assessed for young people aged 16 years or over who receive general paediatric outpatient care where there are concerns that the young person may have an impairment of brain or mind? Yes No
- 40b. Does this always occur? Yes No
- 41a. Is a best interests decision-making process embedded in your service for young people over 16 years of age who have been assessed as not having capacity to make a specific decision at a specific time and in specific circumstances? Yes No
42. Are there systems in place for the views of children and young people to inform service design and delivery? Yes No
43. Are there systems in place for the views of parent carers to inform service design and delivery? Yes No

M. PALLIATIVE AND END OF LIFE CARE

40. Who provides palliative care for children and young people with cerebral palsies under this service? (Please select all that apply)
- | | | |
|---|---|---|
| <input type="checkbox"/> GP | <input type="checkbox"/> General paediatrician | <input type="checkbox"/> Community paediatrician |
| <input type="checkbox"/> Paediatrician with specific expertise in disability (disability, community or general with specific expertise) and palliative care | | |
| <input type="checkbox"/> Paediatric palliative care consultant locally | <input type="checkbox"/> Paediatric palliative care consultant regionally | <input type="checkbox"/> Adult palliative care consultant |
| <input type="checkbox"/> Adult physician | <input type="checkbox"/> Community children's nurse | <input type="checkbox"/> Specialist palliative care nurse |
| <input type="checkbox"/> Other (Please specify) | <input type="text"/> | |

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE



Funding for this study was provided by The Healthcare Quality Improvement Partnership (HQIP) as part of The Clinical Outcome Review Programme into Child Health.

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