Question & Answers

Guidance Notes For Professionals/Local Care Providers

1. Who is eligible to access the CJD Care Package?
Anyone who has been diagnosed with CJD, is in contact with the National Care Team and is currently resident within the United Kingdom and is entitled to NHS care.

2. Can those individuals or their families who have CJD apply directly to access the Care Package?
No. Applications to access the package must come through the relevant professional in the local team. Applications must indicate a genuine need following an assessment by an appropriate professional and the reason why it cannot be funded locally. Local funding issues may relate to waiting times, service not supported locally, delivery time issues etc.

3. Will the person with CJD have to supply details of their income and savings?
   • If care is being funded by Continuing Health Care (CHC) – No.
   • Where the local authority is meeting needs under section 18, 19 or 20 of the Care Act 2014 it has a power to charge under section 14, subject to financial assessment under section 17. However, the local authority must not make a charge for meeting needs under this section, where the care and support is being provided to an adult with variant CJD (see Care And Support (Charging and Assessment of Resources) regulations 2014 section 4).

4. Can People with CJD access the care fund more than once?
Yes. Each application will be considered on an individual basis with the relevant local professional support and assessment.

5. How will payment be made?
No direct payments can be made to individuals, service providers or suppliers. Any payments will only be paid to Continuing Health Care (CHC) Clinical Commissioning Groups (CCG’s) or social services.

6. What is the procedure for applying to the Care Package for funding?
Applications can only be made through the National CJD Care Co-ordinators via lothian.secureCJD@nhs.net or calling 0131 465 9538 If you have the contact details of the relevant care co-ordinator please use this route.

7. What can the funding be used for?
The funding can be used for a wide range of purposes with the underlying proviso that the purpose must directly benefit the person living with CJD.

What can funds not be used for?
Retrospective applications will not be accepted.

IMPORTANT INFORMATION
Since October 2000 the Care package was set up for people with CJD to ensure that shortfalls in care provision were met. It is a sum of money accessed through the national Care Co-ordinators and may provide funding in addition to local authorities, clinical commissioning groups and health care trusts in order to optimise care. It is not to replace local funding.
CARE PACKAGE APPLICATION FORM

Patient Details

Mr  o  Mrs  o  Miss  o  Ms  o  Other  o

Surname: ........................................ First Name:....................................................
Address: ....................................................................................................................
Postcode: ..................................................
Date of Birth: ................................. Age: ..................................................

Type of CJD:

Have you previously received a grant from CJD care fund?  YES / NO  if so please give details

Professional making application:

Name :
Designation:
Contact details:

Who is the CJD Care Co-ordinator involved?

Date of application:  Date of approval:

Please use this box to describe what the funding is for and how will this meet the patient’s needs?
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<thead>
<tr>
<th>Question</th>
<th>Response</th>
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<tr>
<td>Who from the local team has made this assessment?</td>
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<td>Contact details:</td>
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<td>Who will pay for the service/item in the first instance?</td>
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<td>What is the cost of the service/item?</td>
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<td>What is the amount of funding you are requesting?</td>
<td>£</td>
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<tr>
<td>How has the above figure been arrived at?</td>
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