ANNEX 2. INFORMATION TO PATIENTS AND CAREGIVERS

Detailed information should be given. Materials provided by the pharmaceutical company AbbVie (magazines, booklets, pumps, catheters, etc.) may be used. It may sometimes be helpful if patients talk to other patients treated with Duodopa, provided they all agree to do so, to have a more real knowledge of the treatment and be able to ask questions. In any case, we should always be respectful and give the patients the time they need to make their decision, whatever it is.

Adequate information to patients and caregivers is indispensable to achieve good results throughout the process, because this is complex and requires a lot of cooperation. Unreal expectations should not be created, and it should be made clear from the beginning that although the treatment may improve quality of life, it is not free from potential complications. Caregivers should also be explained their essential role and the burden that patient care will represent for them, so that they understand the actual implications of the whole process.

To provide this information, explanatory materials are very helpful for patient and caregiver to review them with their family and become acquainted with the treatment. The specialists involved will subsequently answer any questions.

NURSE PROCEDURE

PATIENT SELECTION PHASE

✚ Assessment of motor signs. Whenever possible, it would be important that the reference nurse knows how the patient behaves in the different motor stages: «on», «off», and with dyskinesia.

✚ Assessment by the nurse of non-motor symptoms such as depression, sleep disorders, pain due to rigidity, constipation, cognitive impairments etc.

✚ Help the patient and/or relative to complete the scales provided by the neurologist, such as EQ-5d Health Questionnaire, PDQ 39, etc.

✚ Instruct the patient on adequate data recording, making reference to «on», «off», or dyskinesia (Annex 1).

✚ Request the required materials: pump, nasoduodenal catheter AbbVie™ NJ and extension tube, starting equipment with the support guidelines for patient and operator.
CANDIDATE PREPARATION

Once the patient has freely decided to be treated with Duodopa after being clearly explained what the treatment consists of and after verifying that he/she is a good candidate, he/she must sign an informed consent. Informed consent should be available before all administrative procedures are started. The corresponding approvals, as appropriate for each center (pharmacy committees, medial management, etc.), must also be available.

Usually, and depending on the hospital, patient will be admitted to first assess response to medication through a nasoduodenal catheter, although this procedure is performed in some centers on an outpatient basis at a day hospital. The date will be scheduled based on availability of (1) patient and family, (2) nurse specialized in Duodopa, and (3) gastroenterologist (PEG surgery).

It is advised to schedule the date of admission or start of outpatient therapy at least 1 month in advance, and to take into account that at least 3 or 4 days will be required (since the date of PEG will be scheduled in advance in many hospitals) to assess whether the patient is a good candidate, and if he/she and his/her family agree to continue with the procedure and finally perform gastrostomy. It is recommended to calculate the equivalent daily dose of levodopa (mg/day) [1] and to adjust the medication at least 15 days before so that the patient is treated with oral levodopa alone at the time Duodopa is started. This is not mandatory, however, and there is evidence that the equivalent dose may be calculated in a patient on polytherapy (levodopa, dopamine agonists, monoamine oxidase B inhibitors –MAOIs–, catechol-ortho-methyltransferase inhibitors –COMTIs–, etc.) and Duodopa may be started immediately [2].
