

# MEDICATION SHORTAGES GUIDELINES FOR ACTION

Guidelines for potential actions in case of  
Parkinson's medication shortages in Europe



*The voice for Parkinson's in Europe*

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# INTRODUCTION

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**T**hese guidelines have been developed to assist EPDA member organisations in dealing with a shortage of Parkinson's medication before it happens, when it happens and after it has happened.

A shortage of one – or more than one – Parkinson's medication at a national level can be particularly disruptive for the Parkinson's community resulting in a major impact on the quality of life of people living with the condition, their families and carers.

Following shortages in several European countries in 2018 of some of the most common Parkinson's medications, the EPDA at their 2019 Members' Meeting organised an expert panel session involving representatives from the European Medicines Agency (EMA), Medicines for Europe

and EPDA member organisations to discuss how the EPDA could help its member organisations resolve the shortage difficulties at a national level. It was agreed that the EPDA could become a contact point between the EU regulatory bodies, the treatment industry and national Parkinson's organisations.

Following discussions with the EPDA Board it was agreed that former Board member Valerie Buxton and EPDA Information Manager and Project Officer, Francesco De Renzis would develop guidelines for potential actions for both the national Parkinson's organisations and the EPDA in case of further Parkinson's medication shortages in Europe.

**Veronica Clark – EPDA President**



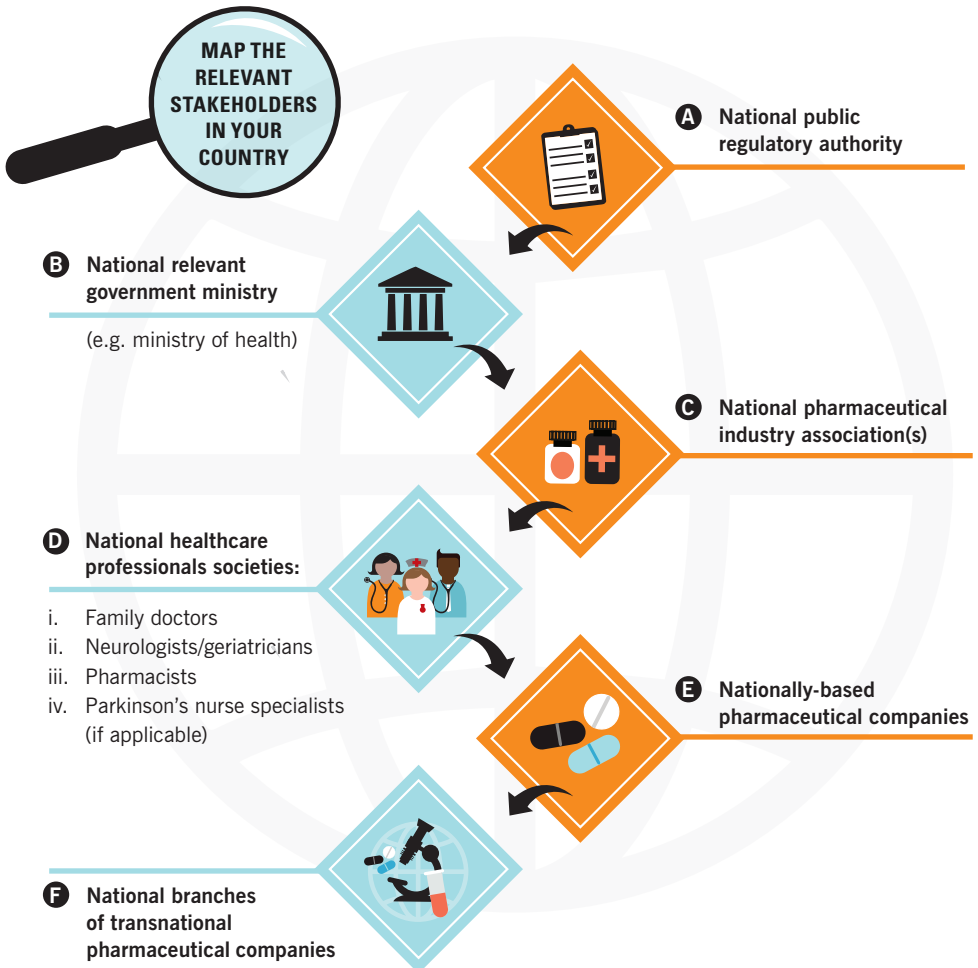
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# ACTIONS FOR NATIONAL PARKINSON'S ORGANISATIONS

## ► Before a shortage happens

### 1. Mapping relevant stakeholders in your country





## ESTABLISH RELATIONSHIPS

### 2. Establishing relationships:

- A** Get in contact with each relevant stakeholders
- B** Position your organisation as a first point of contact for information about the national supply of Parkinson's medication

### 3. Identifying your audience:

- A** People with Parkinson's
- B** Family members and care partners
- C** Healthcare professionals
- D** Local Parkinson's organisations and formal/informal support groups



## IDENTIFY YOUR AUDIENCE



## IDENTIFY COMMUNICATION CHANNELS

### 4. Identifying communication channels you can use to disseminate information about medicines supply:

- A** Website
- B** E-newsletter
- C** Social media channels
- D** Phone helpline
- E** Printed publications
- F** Online forums, blogs and groups



### 5. Set out key general messages to disseminate to your audience quickly in the event of a shortage – for example:

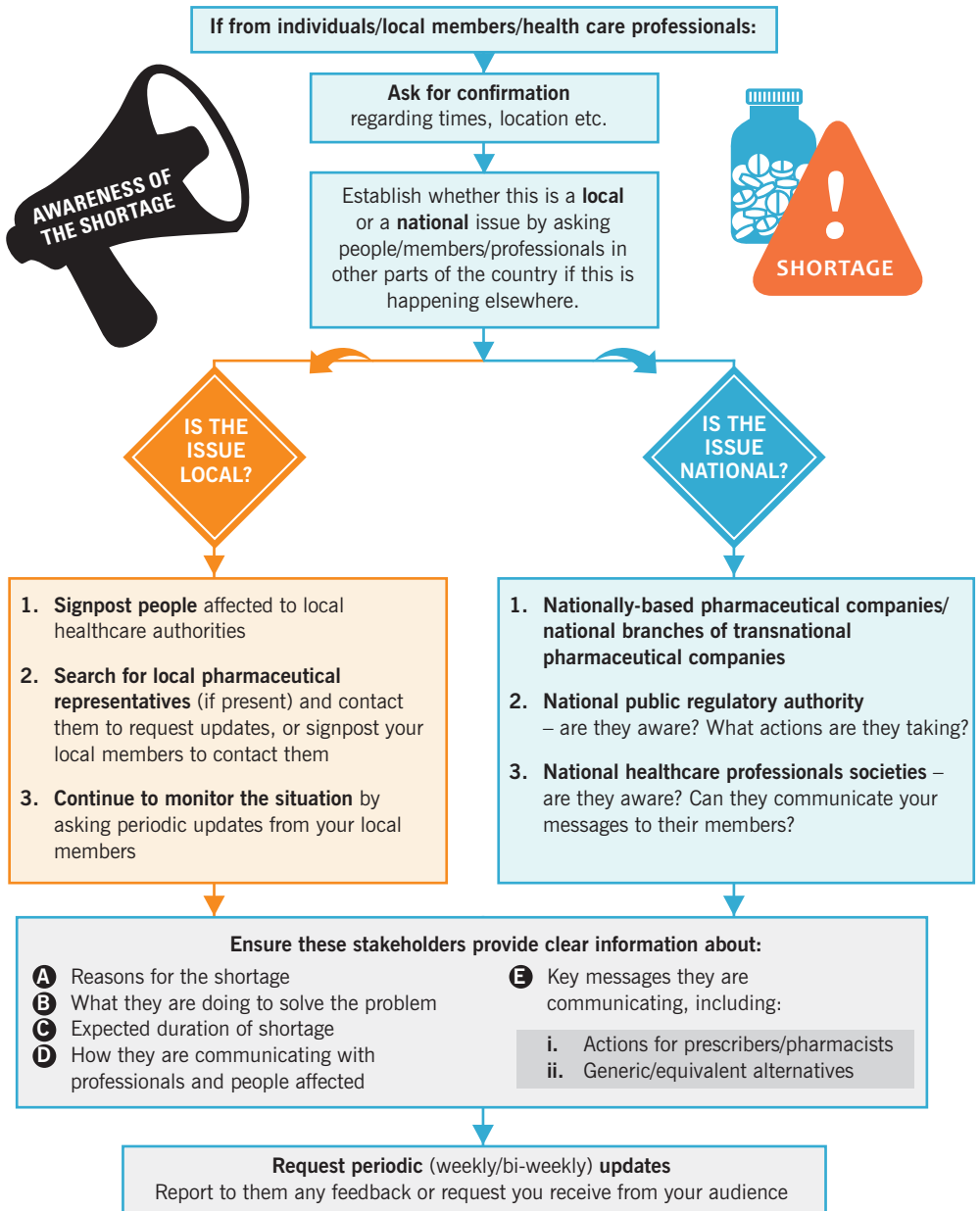
- A** Avoid stockpiling (for individuals and families)
- B** Basic information about generic/equivalent alternatives available (for healthcare professionals, individuals and families)




## KEY MESSAGES TO YOUR AUDIENCE

## ► When a shortage happens

### 1. How has your association been made aware of the shortage?





## 2. Communicate to your audience via your identified communication channels

- A** Any information you disseminate must:
- ✓ i. Be verified and factual
  - 🕒 ii. Be timely and up to date
  - 📄 iii. Be written in a clear and understandable language
  - 💡 iv. Not be written in a way that could be misleading or create panic
  - 🏥 v. Signpost audience to sources, useful resources and contact persons (healthcare professionals)
  - 🔄 vi. Provide indications about generic/equivalent alternatives

- B** Keep the flow of communication regularly ongoing for the whole shortage period, providing regular updates that are consistent through all chosen channels

## 3. Gather feedback from:

- A** **Individuals** - Is the shortage ongoing in their area? How are they managing through the period? Are they finding your information helpful?

**TIP:** Do not only collect 'dry' data (what, where, when), but also personal stories and testimonies from individuals and families about their difficulties, and the impact the shortage is having on their life and well-being

- B** **Local associations** - Is the shortage ongoing in their area? How are they helping their local members? Are they finding your information helpful?

- C** **Healthcare professionals** - Do they receive complaints from their patients/customers? How are they helping them? Are they disseminating your information? Is it being well received?



## 4. Report feedback to:

- A** National public regulatory authority
- B** National pharmaceutical industry association(s)
- C** National healthcare professionals societies
- D** Nationally-based pharmaceutical companies
- E** National branches of transnational pharmaceutical companies



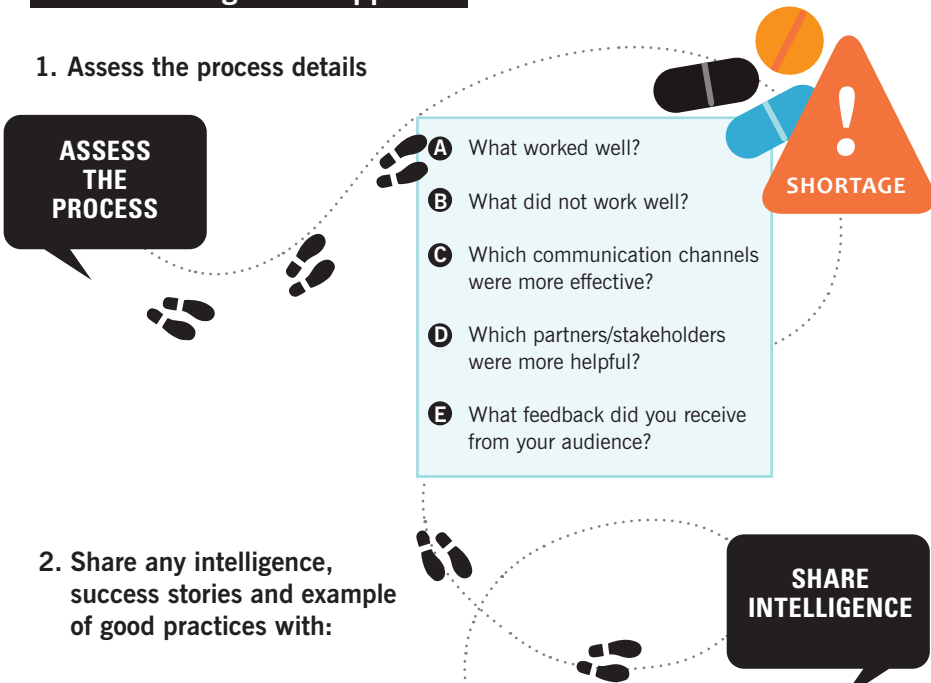

**TIP:** storytelling can be really powerful. Do not only report figures or formal complaints, but also personal stories and testimonies on how the medicines shortage is impacting people and families. This kind of communication can be really effective in driving change and pushing public/private bodies to act.

- F** National politicians/decision makers

## ▶ After a shortage has happened

### 1. Assess the process details


#### ASSESS THE PROCESS

- 
- 
- A** What worked well?
  - B** What did not work well?
  - C** Which communication channels were more effective?
  - D** Which partners/stakeholders were more helpful?
  - E** What feedback did you receive from your audience?

SHORTAGE

### 2. Share any intelligence, success stories and example of good practices with:

#### SHARE INTELLIGENCE

- 
- A** National Parkinson's associations in other countries
  - B** The EPDA
  - C** Other patient organisations in your country
  - D** Healthcare professional organisations
  - E** Regulatory bodies
  - F** Treatment industry organisations
  - G** National politicians/decision makers

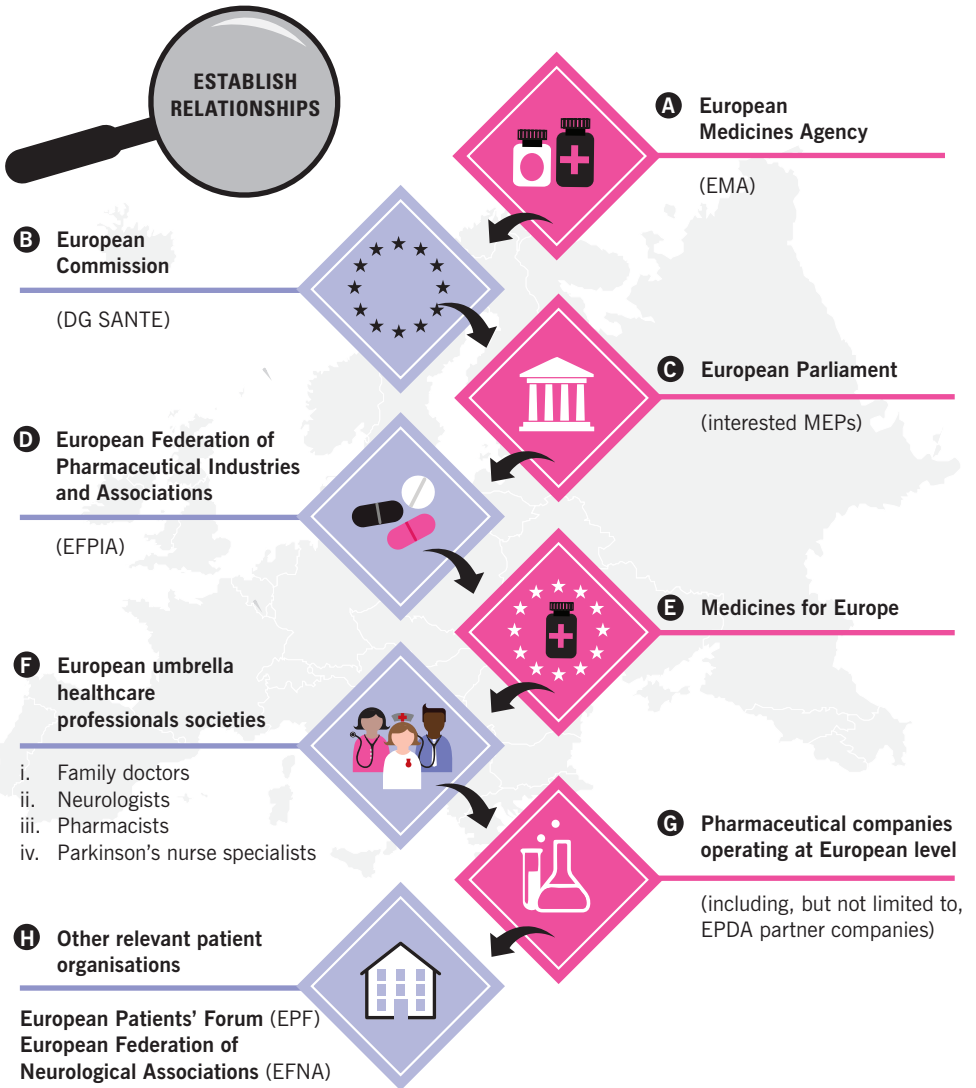
### 3. Keep the communication ongoing on a regular basis with:

#### KEEP COMMUNICATION GOING

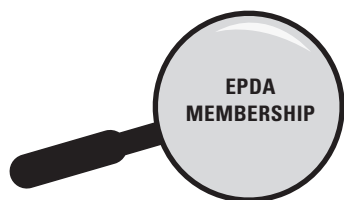
- 
- A** National public regulatory authorities
  - B** National pharmaceutical industry association(s)
  - C** National healthcare professional societies
  - D** Nationally-based pharmaceutical companies
  - E** National branches of transnational pharmaceutical companies

# ACTIONS FOR THE EPDA

## ► Before a shortage happens ► 1. Establish relationships with relevant stakeholders operating at European level:



- 2. Help national Parkinson's organisations trying to build relationships with relevant stakeholders operating at European level.



The EPDA membership is wider than the EU/EEA region. Given its position of European umbrella association, the EPDA can help facilitate connections and communications between patient organisations from neighbouring countries and EU regulatory bodies or decision makers, if necessary.



- 3. Identify communication channels that can be used to disseminate information about medicines supply:



**A** Website



**C** Social media channels



**D** Members forum



**B** Members e-newsletter



**E** Direct emails/ mailing lists



**F** Parkinson's Life

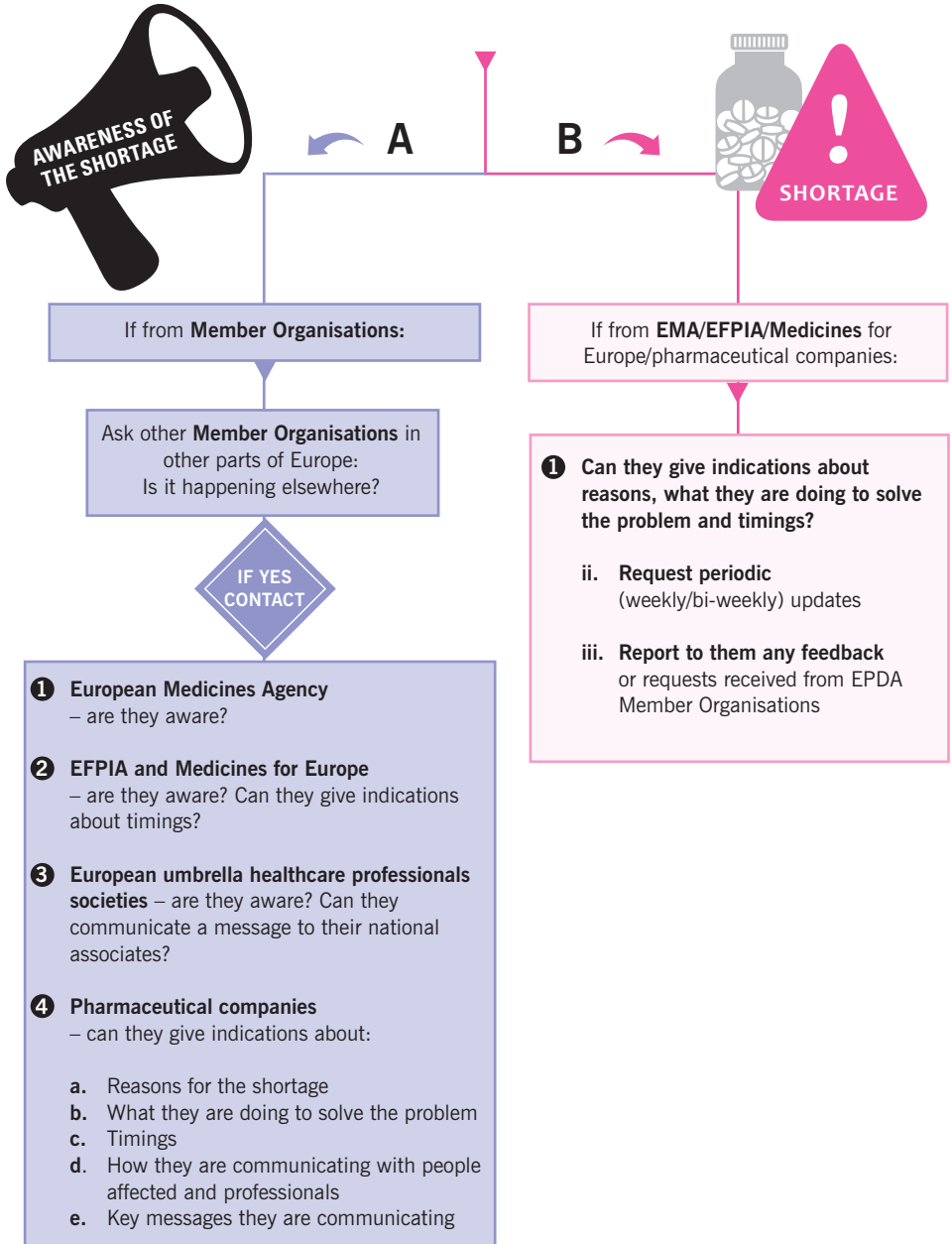
- 4. Identify policy levers that can help ensure disruptions to medicines supply chain are minimised.



Work with relevant stakeholders (see Page 10) to influence policies on the topic, presenting the impact of medicines shortages on people affected using a 'storytelling' approach.

## ▶ When a shortage happens

### 1. How has the EPDA been made aware?





## 2. Communicate to EPDA Member Organisations via identified communication channels

- A** Any information must:
- ✓ i. Be verified and factual
  - 🕒 ii. Be timely and up to date
  - 📄 iii. Be written in a clear and understandable language
  - 💡 iv. Not be written in a way that could be misleading or create panic
  - 📍 v. Signpost audience to sources, useful resources
- B** **Keep the flow of communication regularly ongoing** for the whole shortage period, providing regular updates that are consistent through all chosen channels.

## 3. Gather feedback from:

- A** **Member Organisations** – Is the shortage ongoing in their country? How are they helping their local members? Are they finding EPDA information helpful?
- B** **Healthcare professional societies** – do they receive updates from their national members? How are they helping them? Are they disseminating your information? Is it being well received?



## 4. Report feedback to:

- A** EMA
- B** EFPIA
- C** Medicines for Europe
- D** European Commission
- E** European Parliament (interested MEPs)

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▶ **After a shortage has happened**

1. Assess the process detailed above

**ASSESS  
THE  
PROCESS**

- 
- A** What worked well?
  - B** What did not work well?
  - C** Which communication channels were more effective?
  - D** Which partners/stakeholders were more helpful?

**SHORTAGE**

2. Keep the communication ongoing on a regular basis with relevant stakeholders

**SHARE  
INTELLIGENCE**

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## CONTACT US

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