under pressure

living with Multiple Sclerosis in Europe

Objectives

To investigate how national health and social policies influence – ***for better or worse*** – daily life for people with Multiple Sclerosis.

How to achieve this objective

- A **photojournalistic investigation** of how well EU countries are implementing the **European Code of Good Practice in MS**, as adopted by the European Parliament.
- A means of **allowing persons with MS to tell their own stories** of how the disease impacts their lives.

Objectives

- To **humanise the data** collected through the MS Barometer.
- To **provide a high-impact means of comparing** (across 11 countries) how health and social policies either alleviate or relieve the burden of MS.
- To **show policy makers** what it feels like to have MS – ***right here, right now***.

Project elements

Five elements:

- photo exhibition and book
- multi-media website, featuring web documentary and interactive elements
- awareness-raising brochure
- MS image bank (for use by all EMSP members and project sponsors).

Lead partner

European Multiple Sclerosis Platform (EMSP)

- Patient advocacy group that lobbies on behalf more than 600 000 people with MS across Europe.
- Provides the **UNDER PRESSURE** Creative Team with direct access to MS societies in 34 European countries.

Reportage in 11 countries

- Belarus
- Estonia
- Germany
- Greece
- Iceland
- Ireland
- Italy
- Poland
- Romania
- Spain
- United Kingdom

Material acquired

- 30,000+ photographs
- 10,000+ video clips
- 30+ patient interviews (video)
  - Diverse ages and stages of disease, living conditions, etc.
- 20+ expert interviews (video)
  - Neurologists, psychologists, physiotherapists, MS Nurses, rehabilitation specialists, health economist

Key findings

- **Belarus:** access to medication is very low; disability is high as is social isolation.
- **Estonia:** access to drugs is quite high; social stigma, PwMS do not reveal they are ill.
- **Germany:** Exceptional access to all needs.
- **Greece:** MS Society made many gains, but fears they will be lost due to economic crisis.
- **Iceland:** Access to all treatment is high; MS Centre creates strong sense of community.

Key findings

- **Ireland**: Severe shortage of neurologists.
- **Poland**: Access to treatment low, particularly DMDs; PwMS face high personal costs.
- **Romania:** Access to drug reasonably good; low rehabilitation.
- **Spain:** Dependency law is less effective than hoped; access to rehabilitation is low.
- **United Kingdom:** Access to treatment inconsistent; evolution of disability pension.

A word of THANKS!

Platinum

- Merck Serono
- Almirall
- Biogen Idec

Gold

- Sanofi-Aventis

Silver

- UK MS Society
- Novartis

Selenium

- Bayer
- Synthon
- Italian MS Society

Paper

- Bionorica
- GW Pharma
- TEVA
- Personal donations

UNDER PRESSURE

NEXT STEPS

Planned events

- **24 April 2012:** Official launch at European Parliament
- **April 2012:** Electronic Exhibition in UK, MS Life
- **May 2012:** Exhibition in Barcelona, as part of EMSP 2012 Annual Congress
- **May 2012:** Estonia, the Netherlands
- **Fall 2012:** Poland, Romania

BELARUS / Walter ASTRADA

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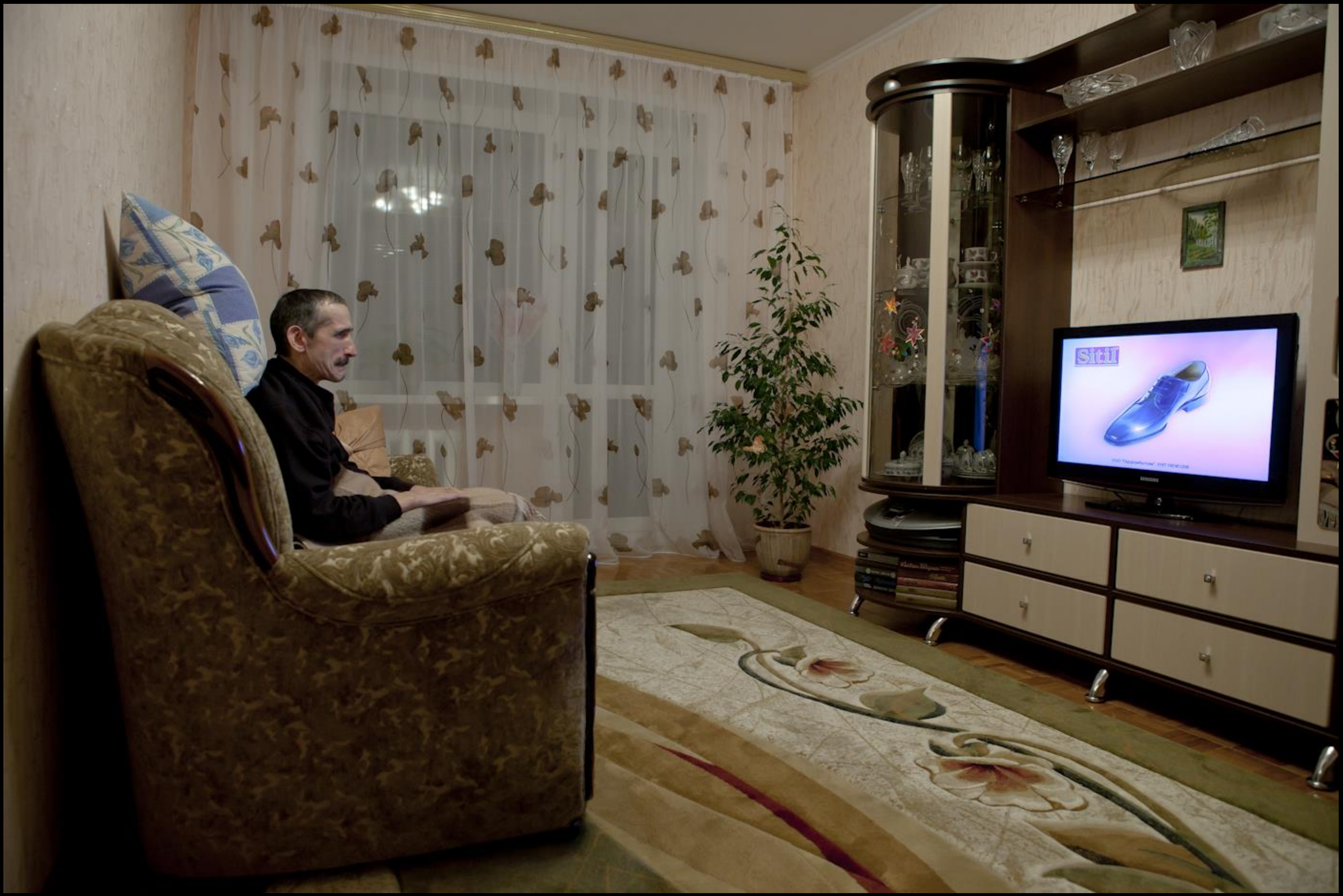

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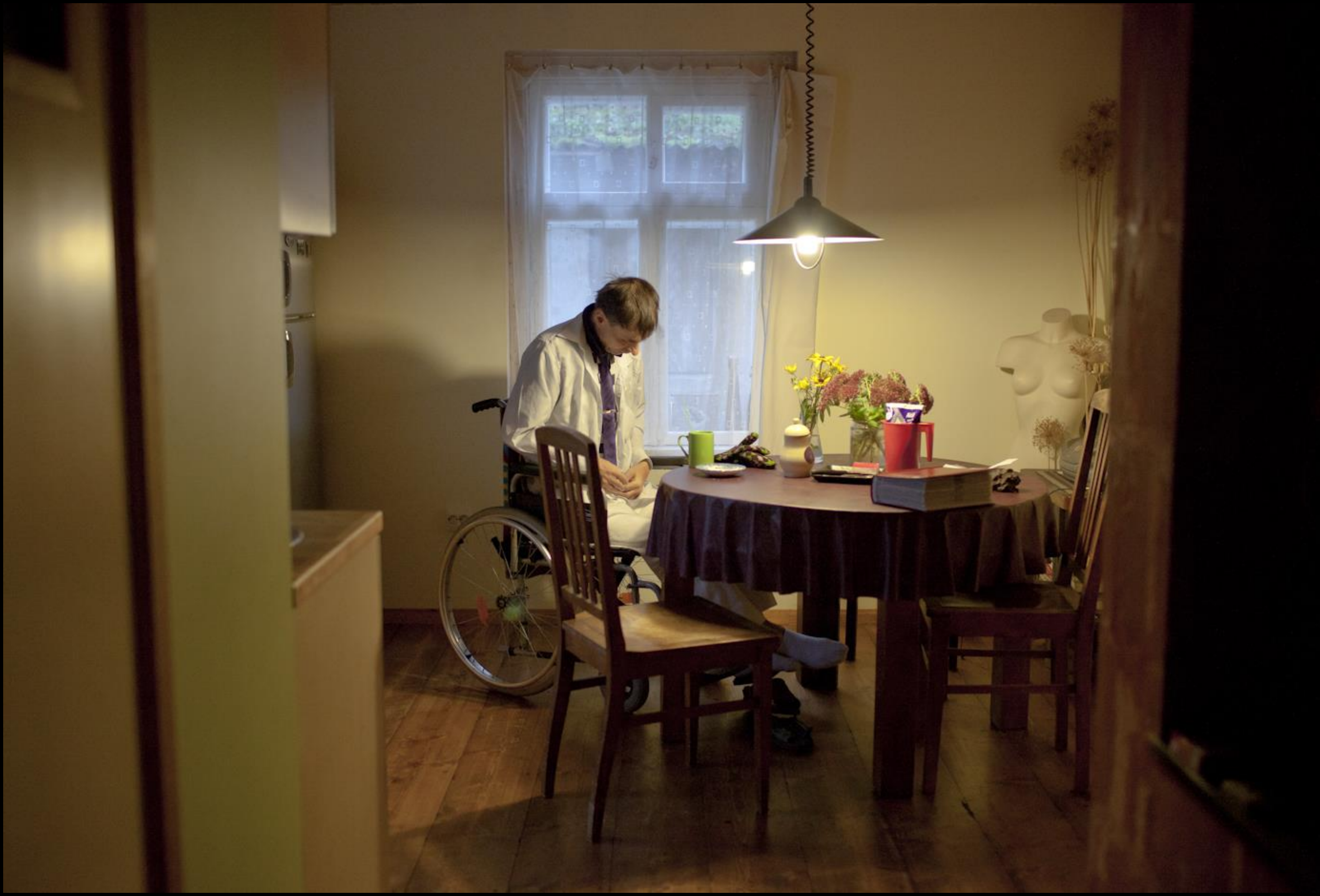

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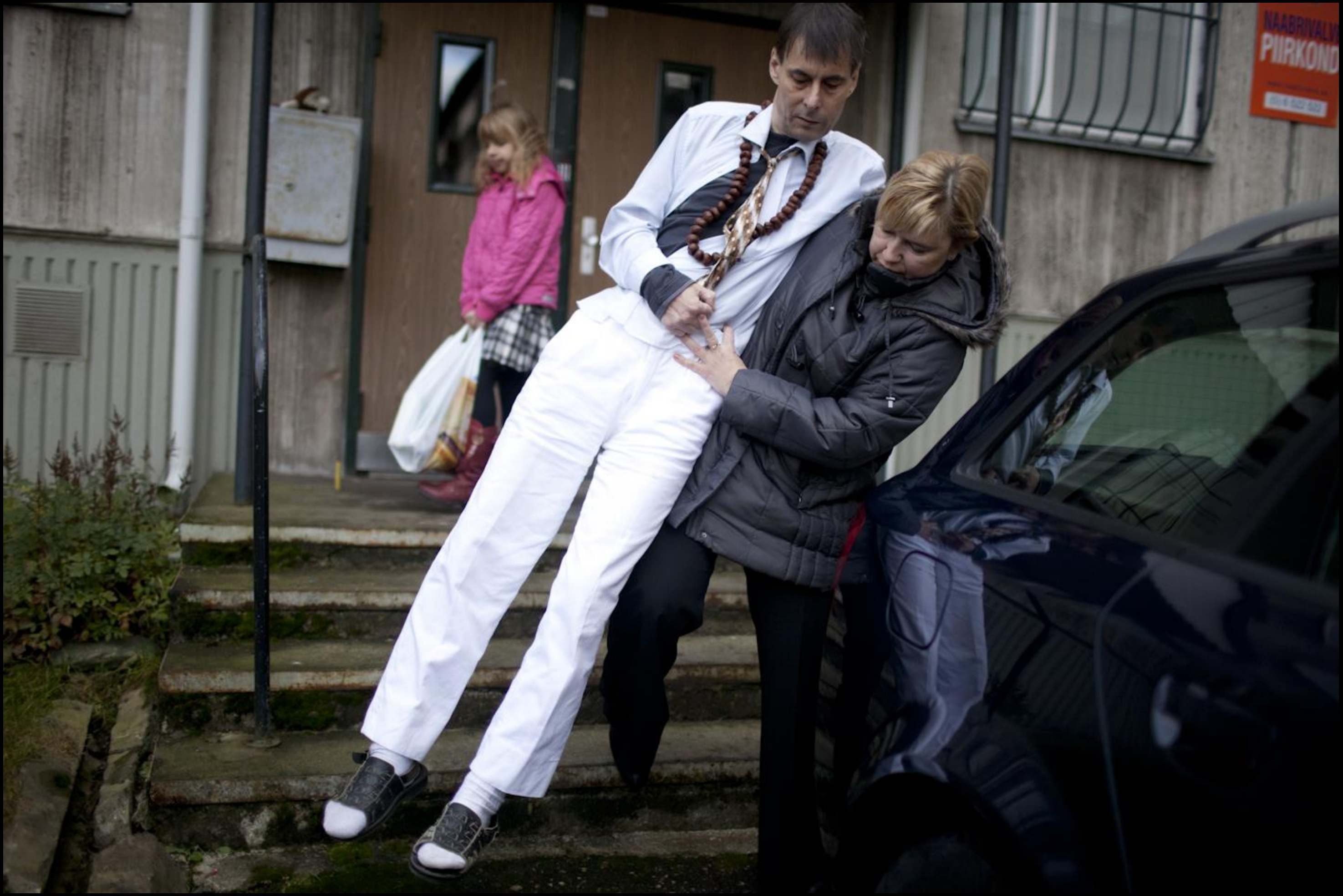

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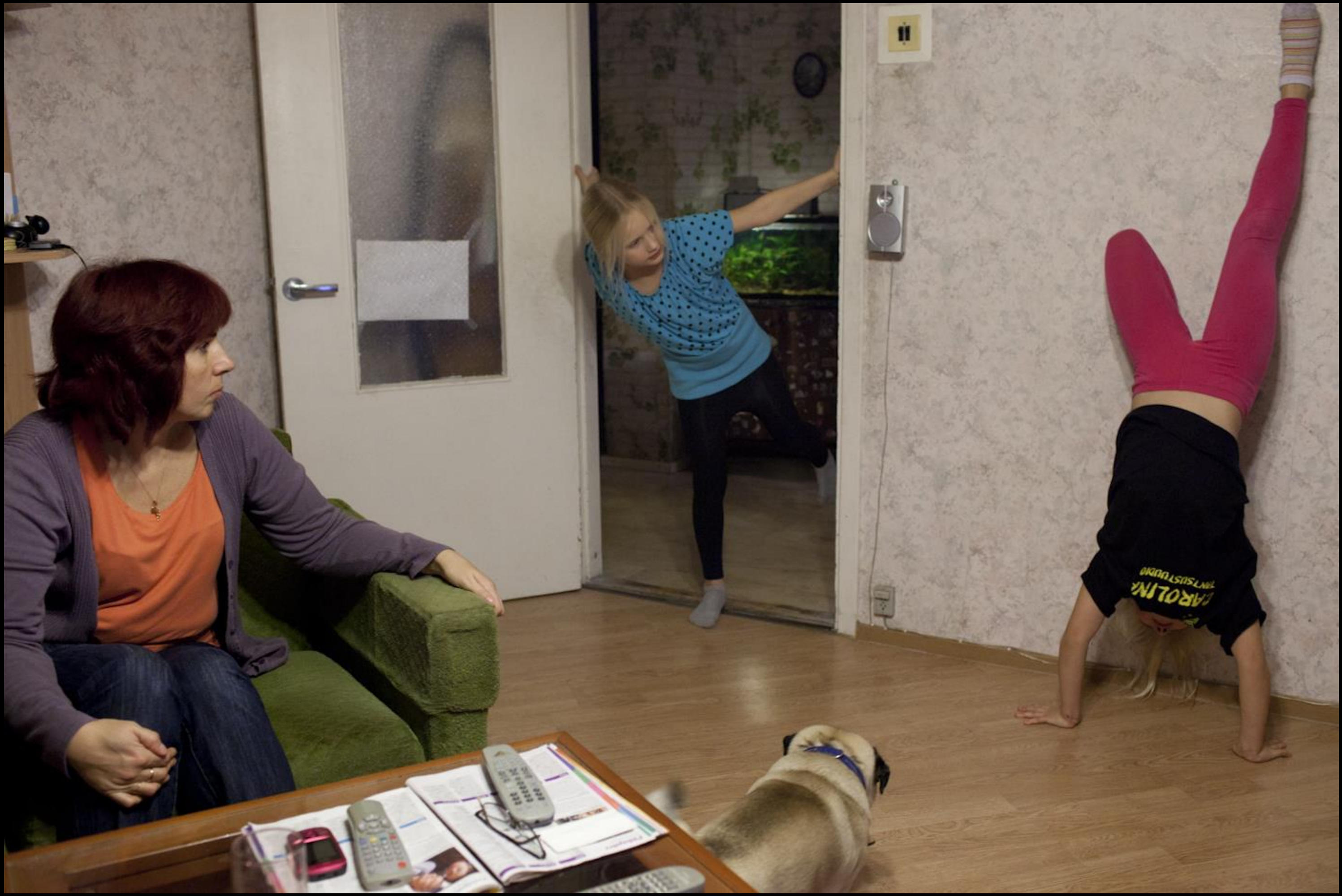

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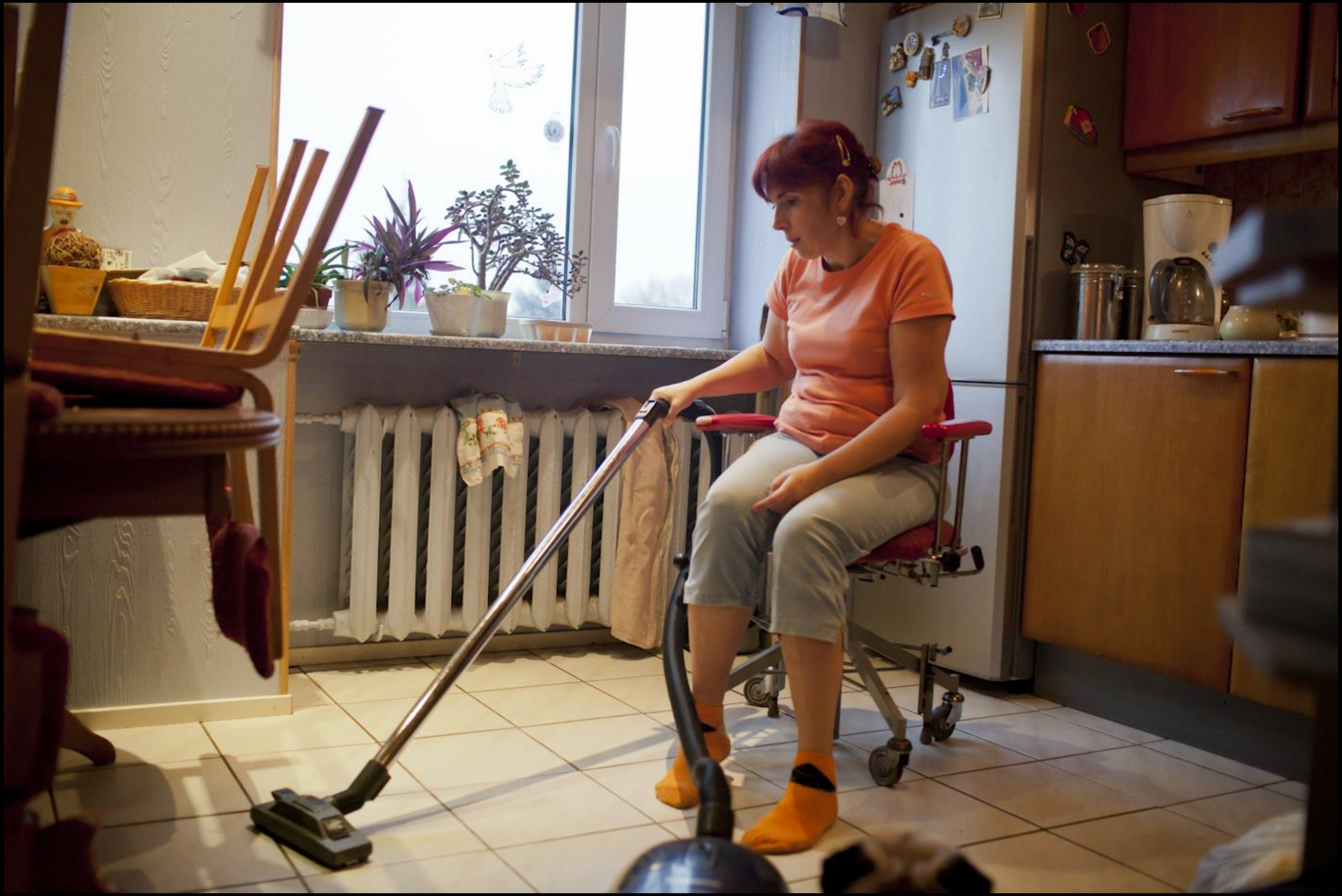

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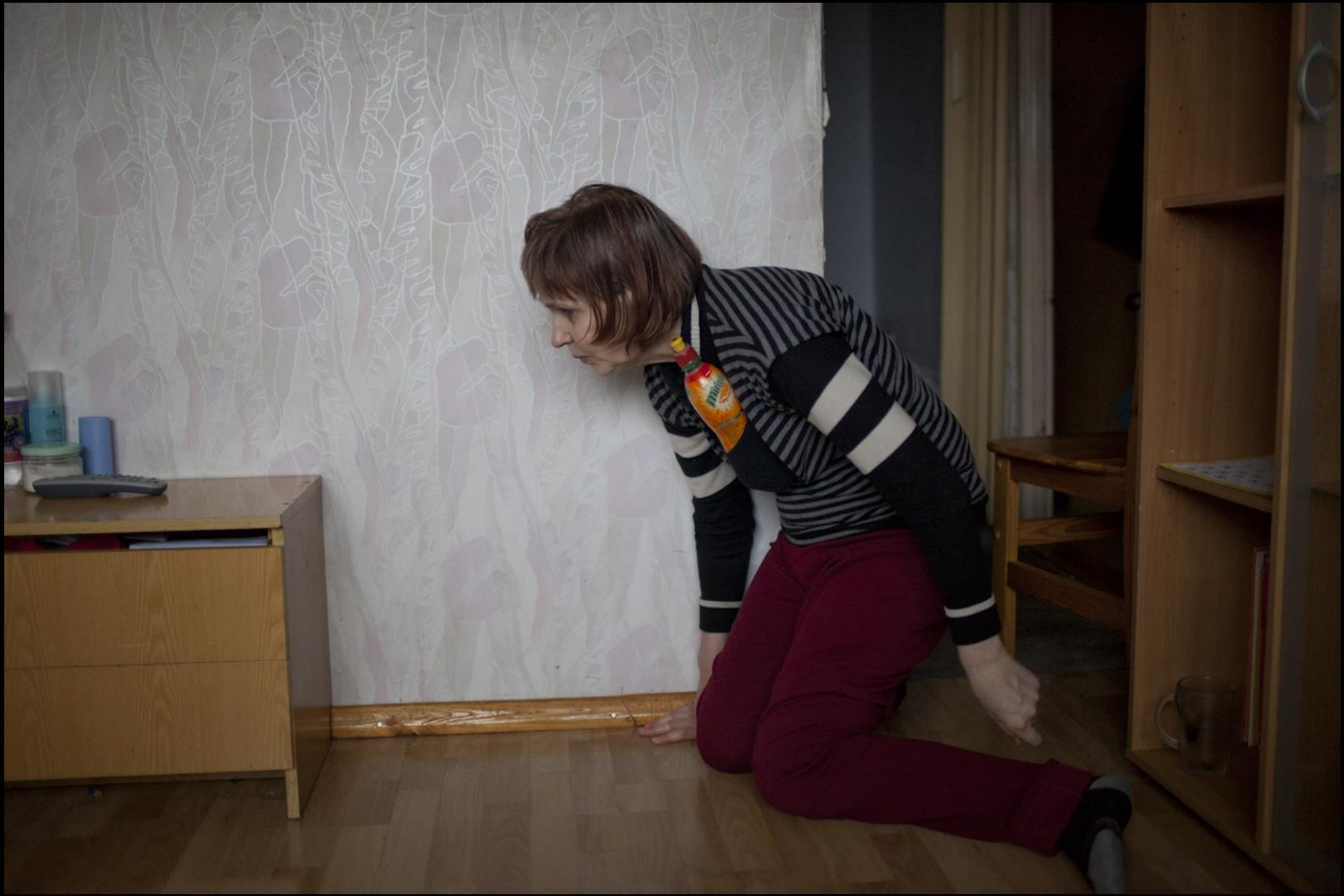

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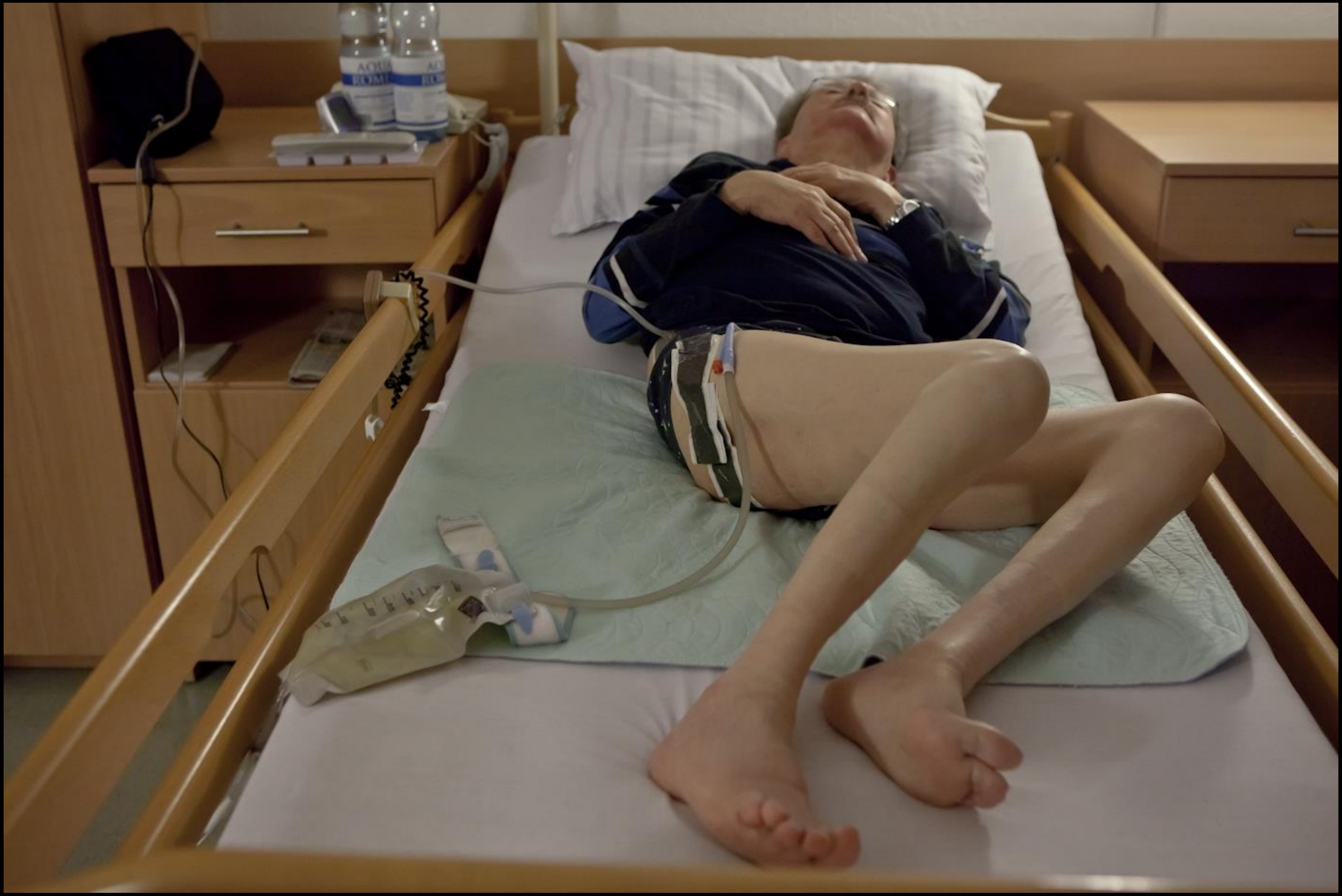

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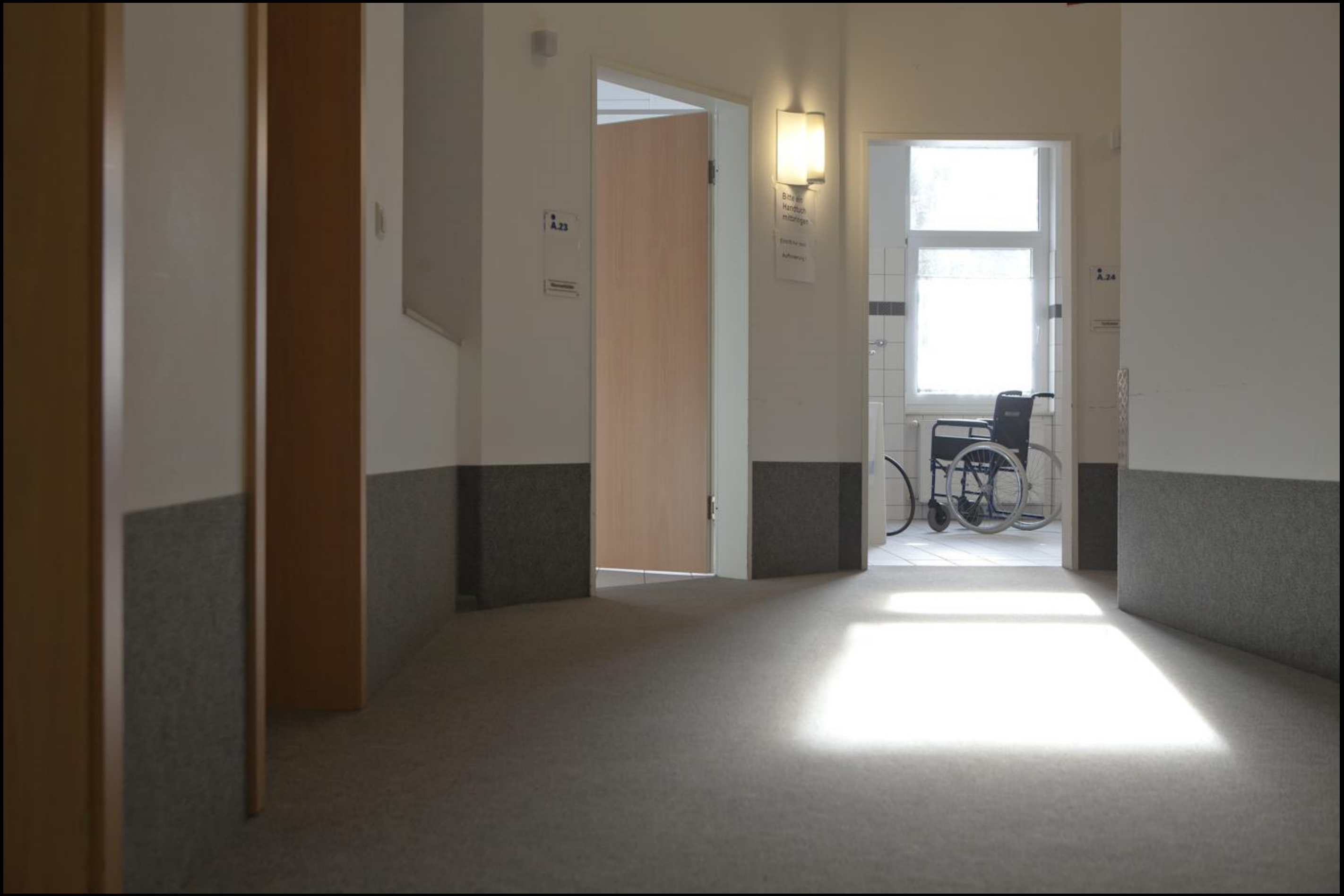

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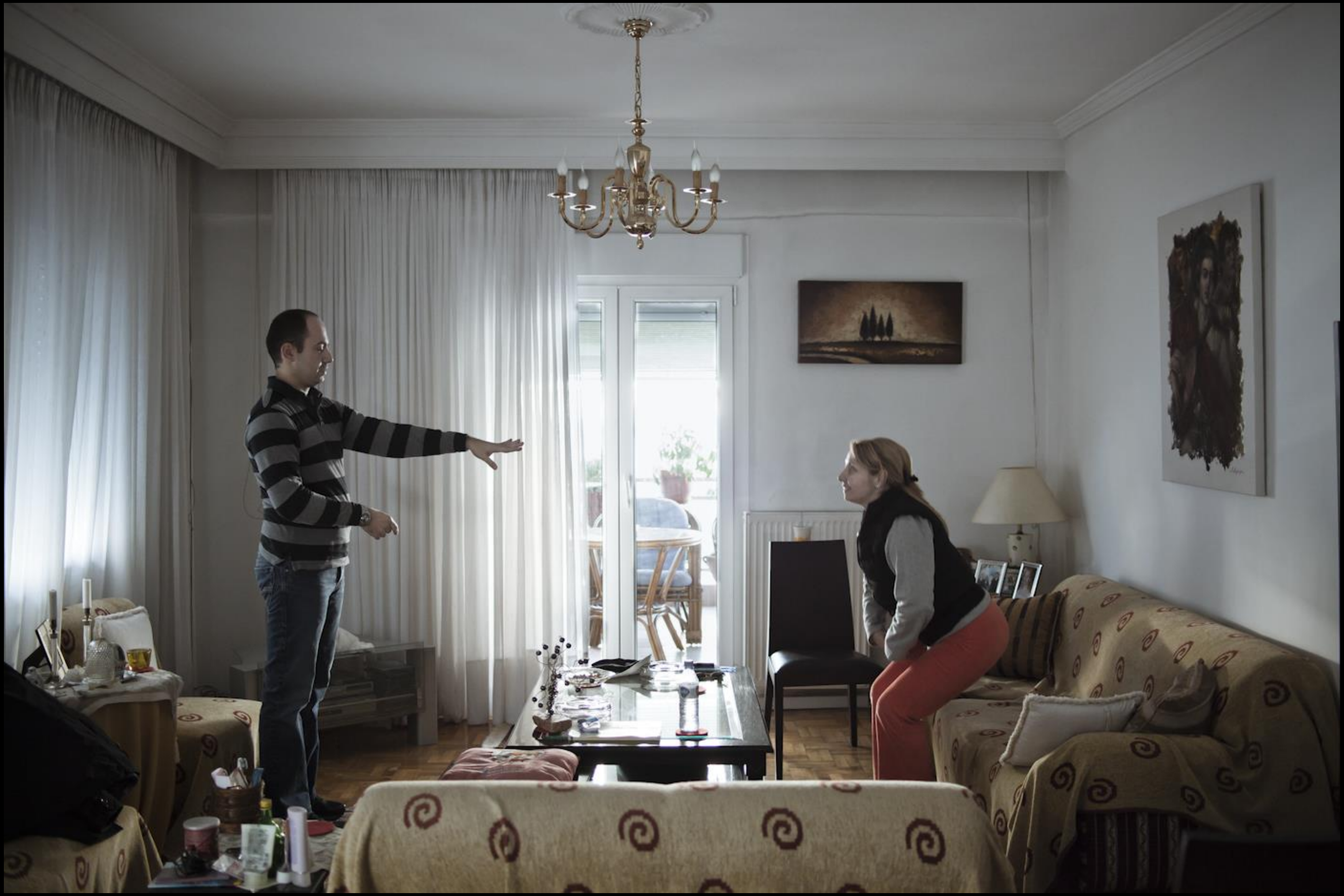

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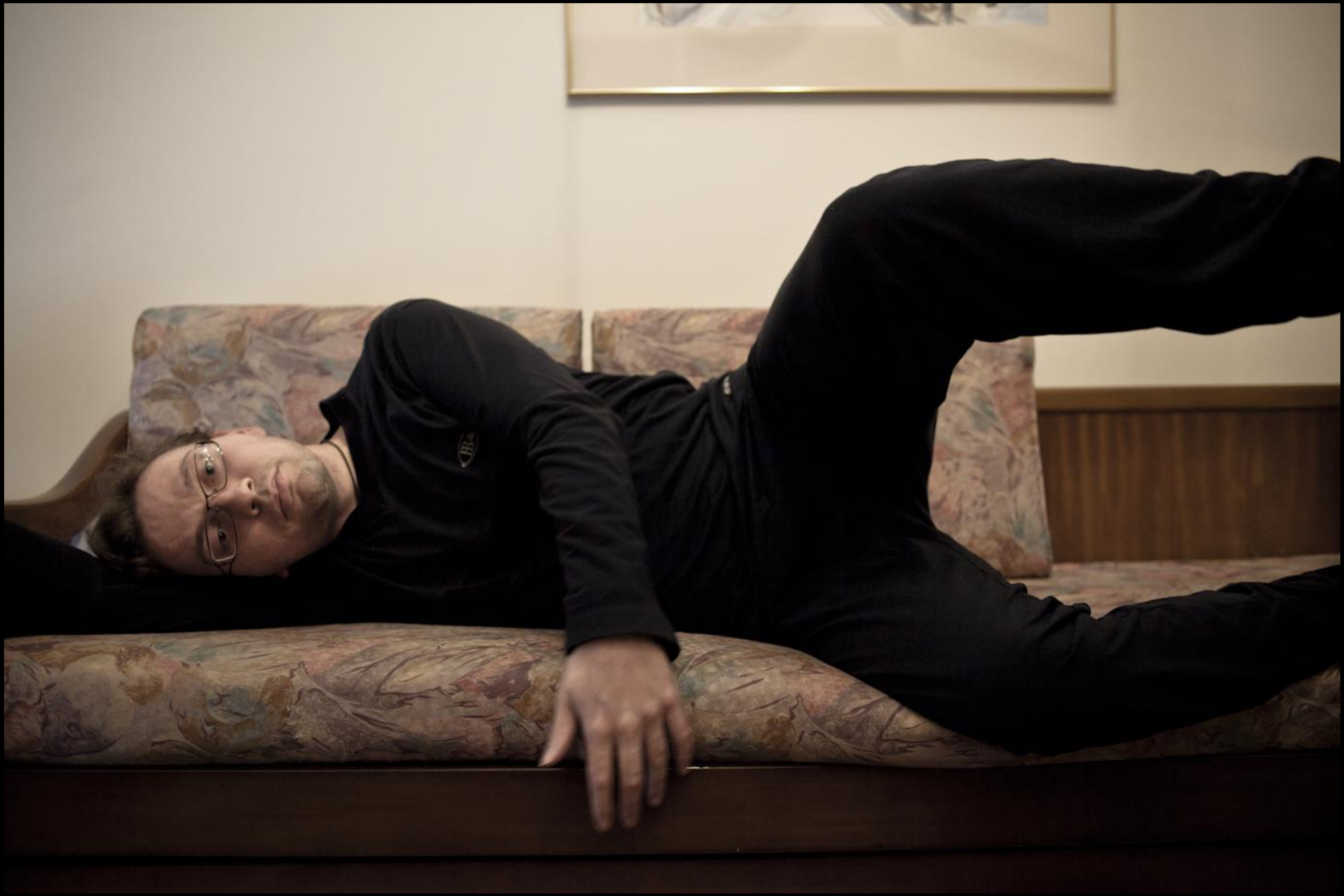

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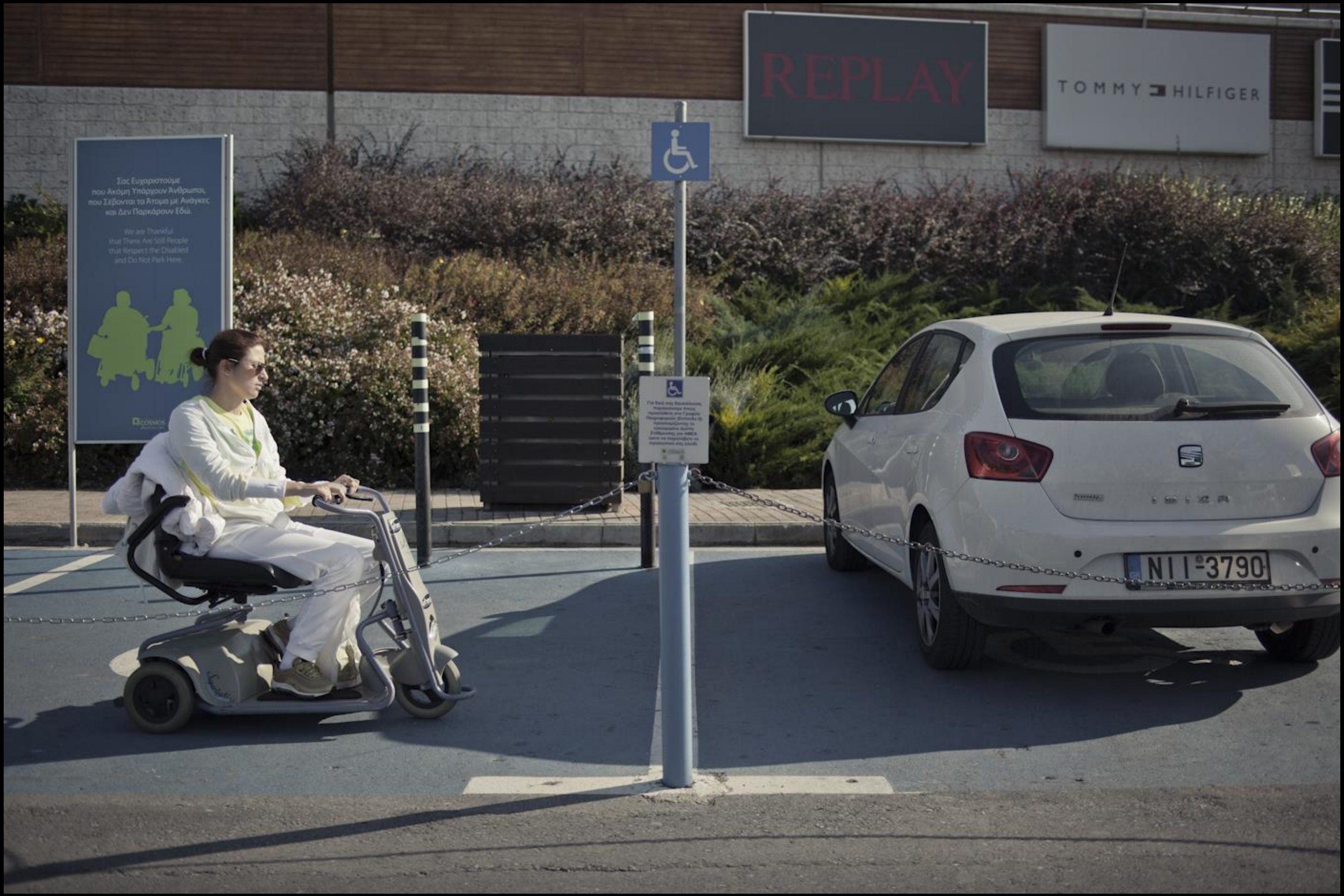

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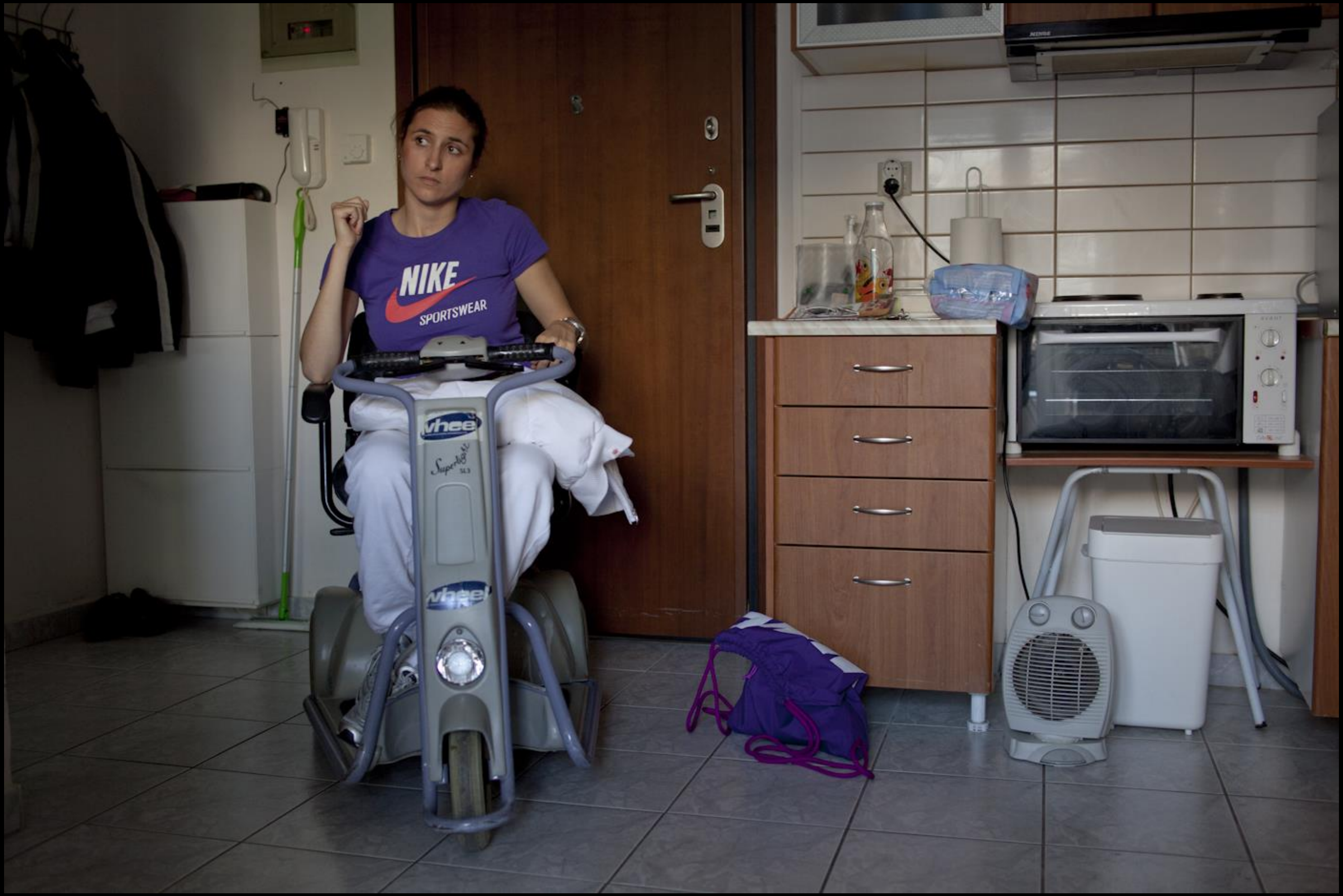

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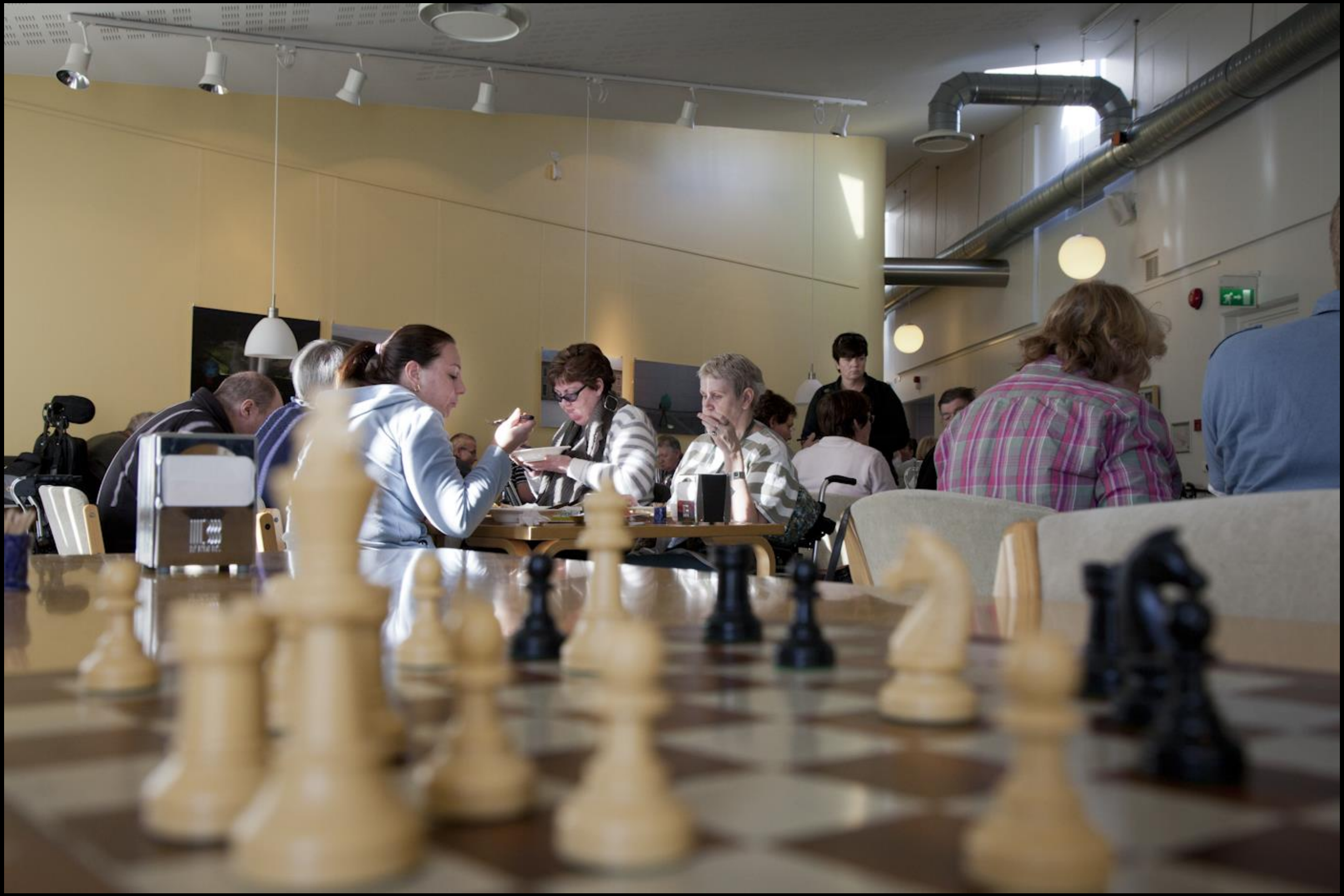

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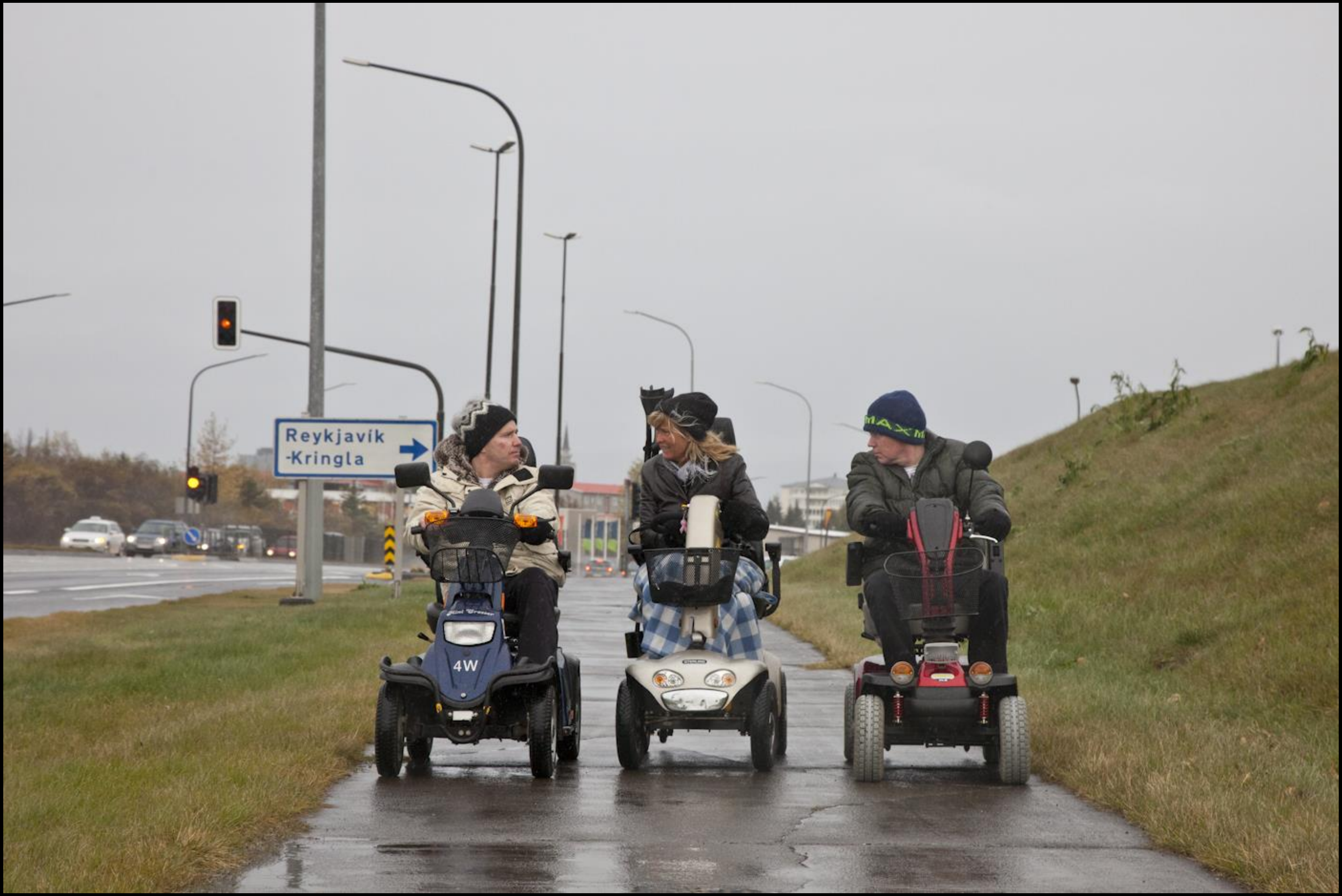

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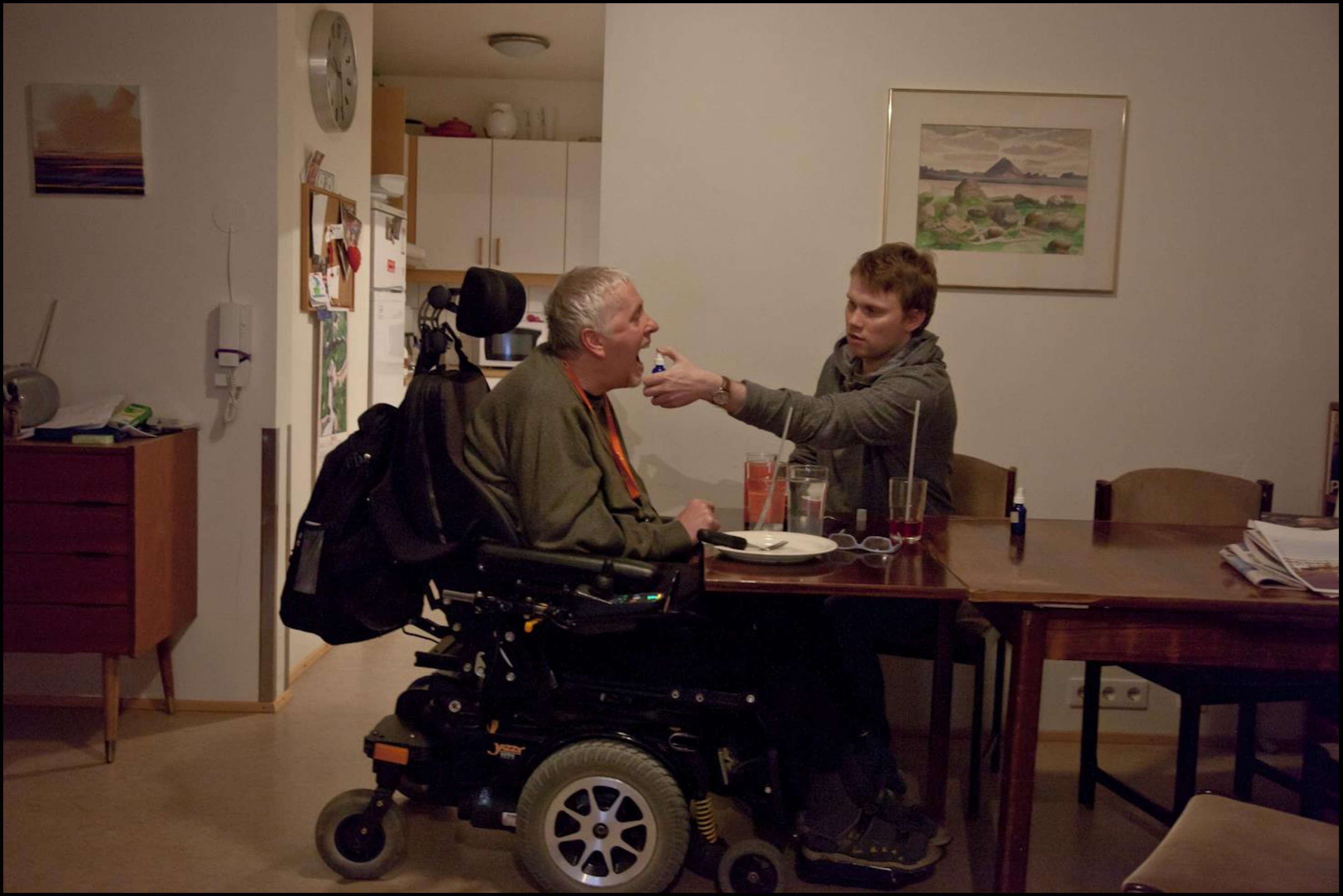

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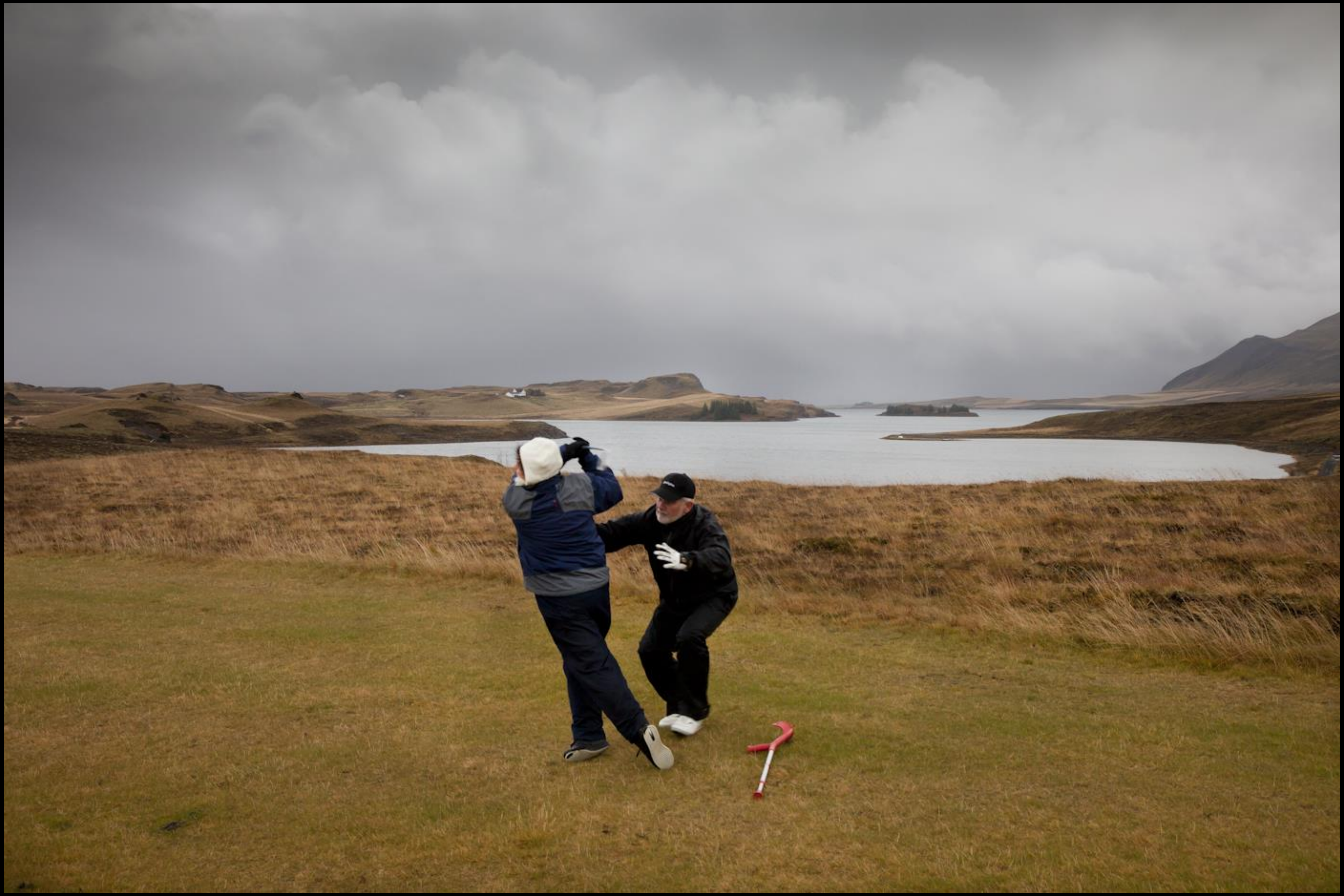

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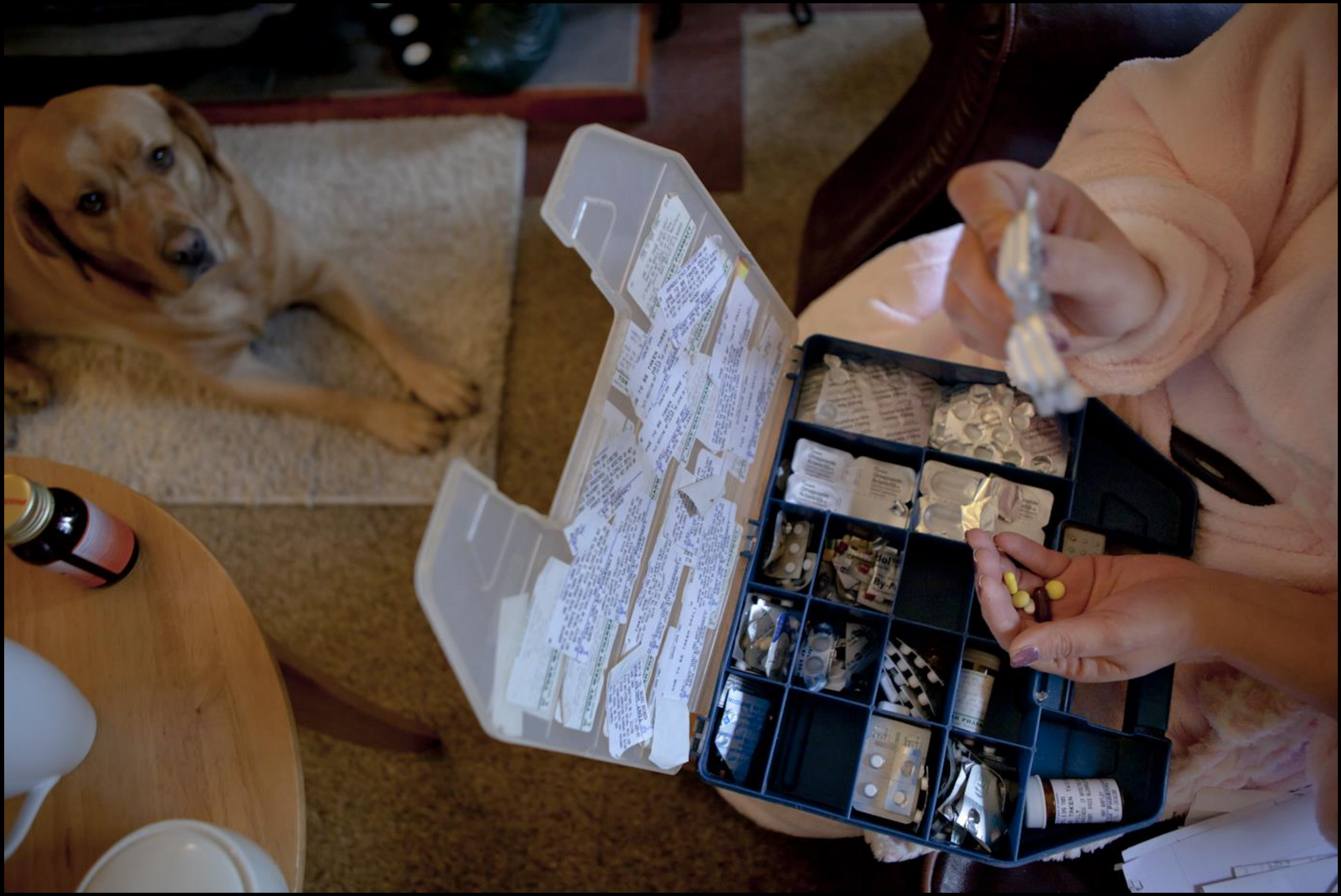

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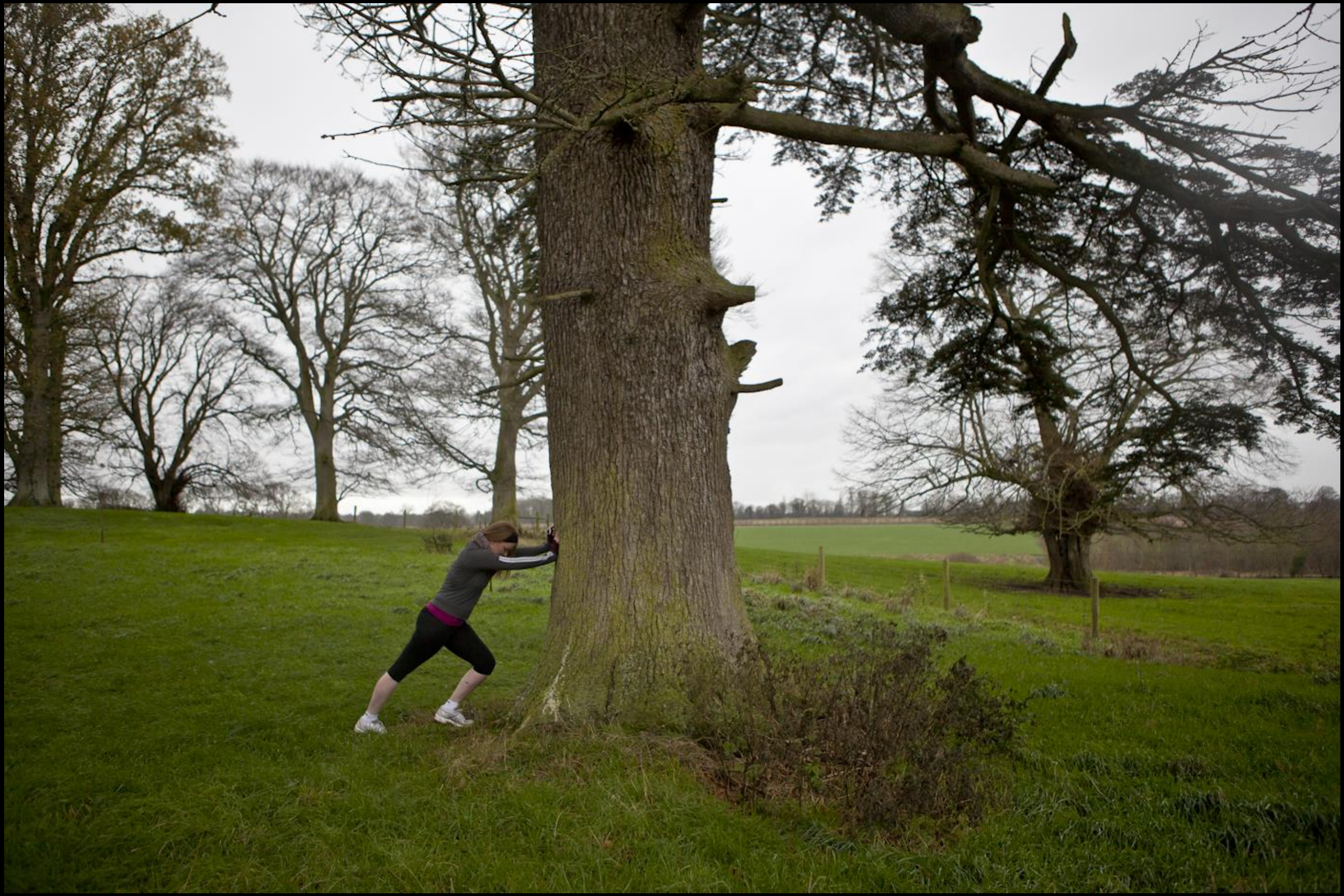

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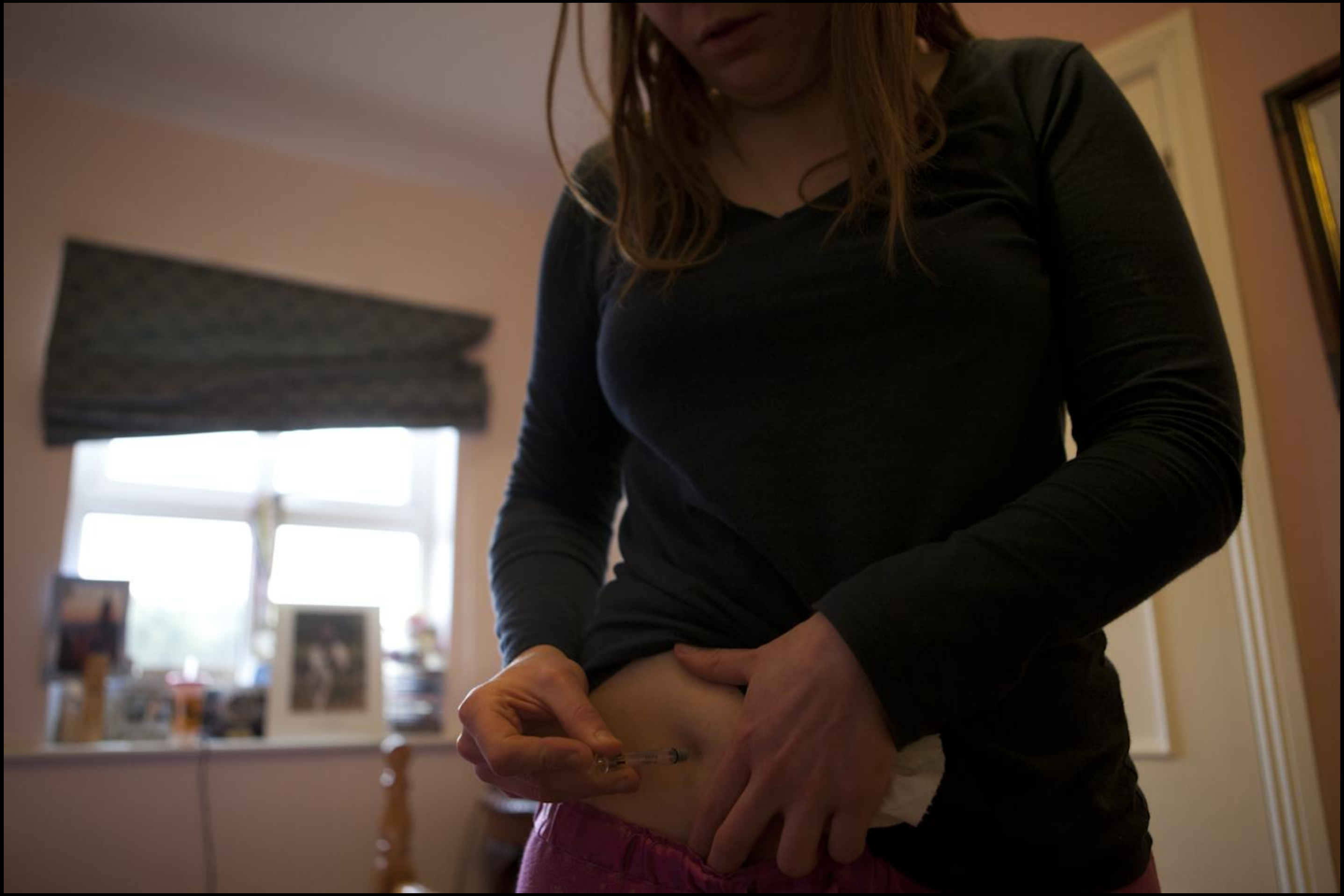

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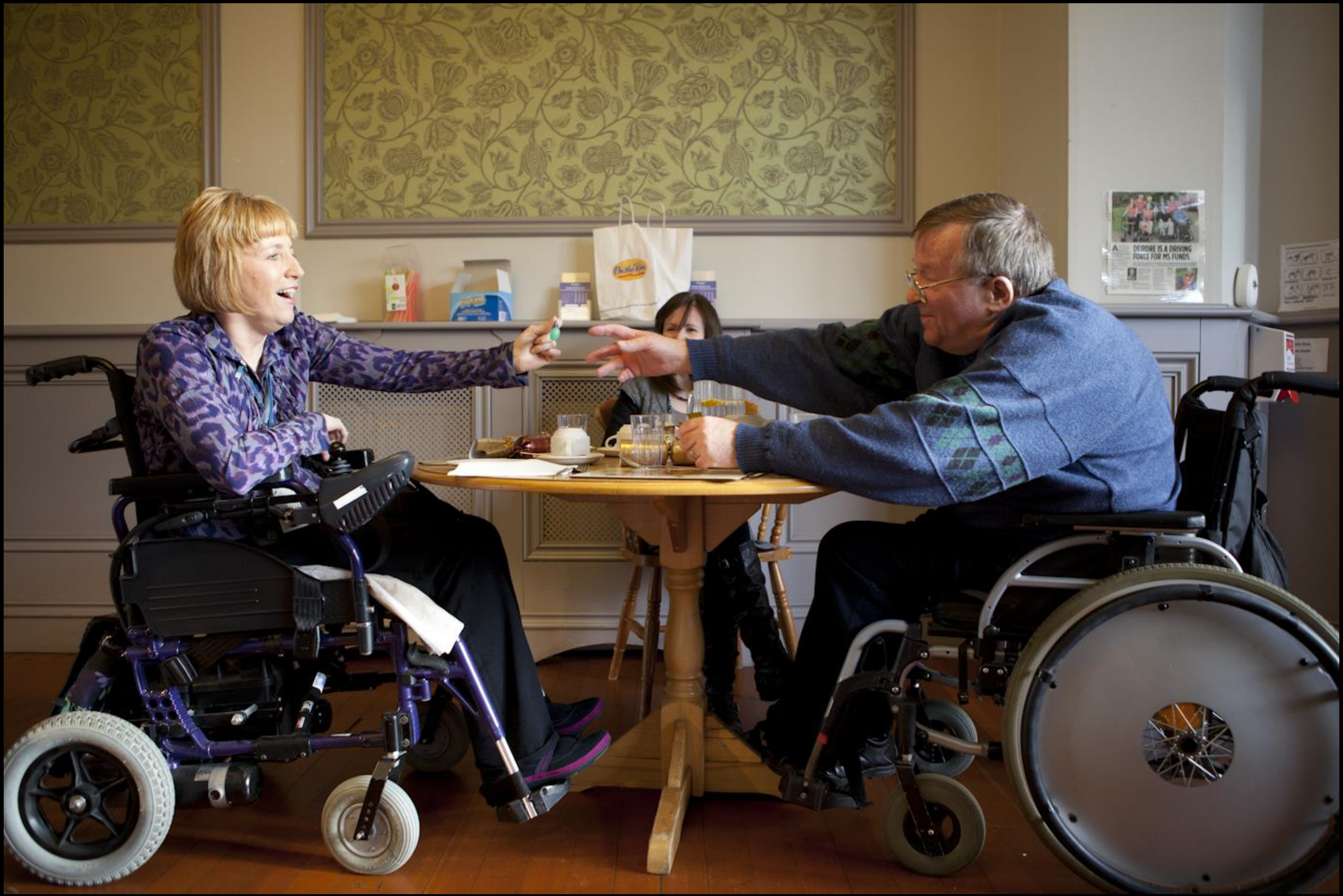

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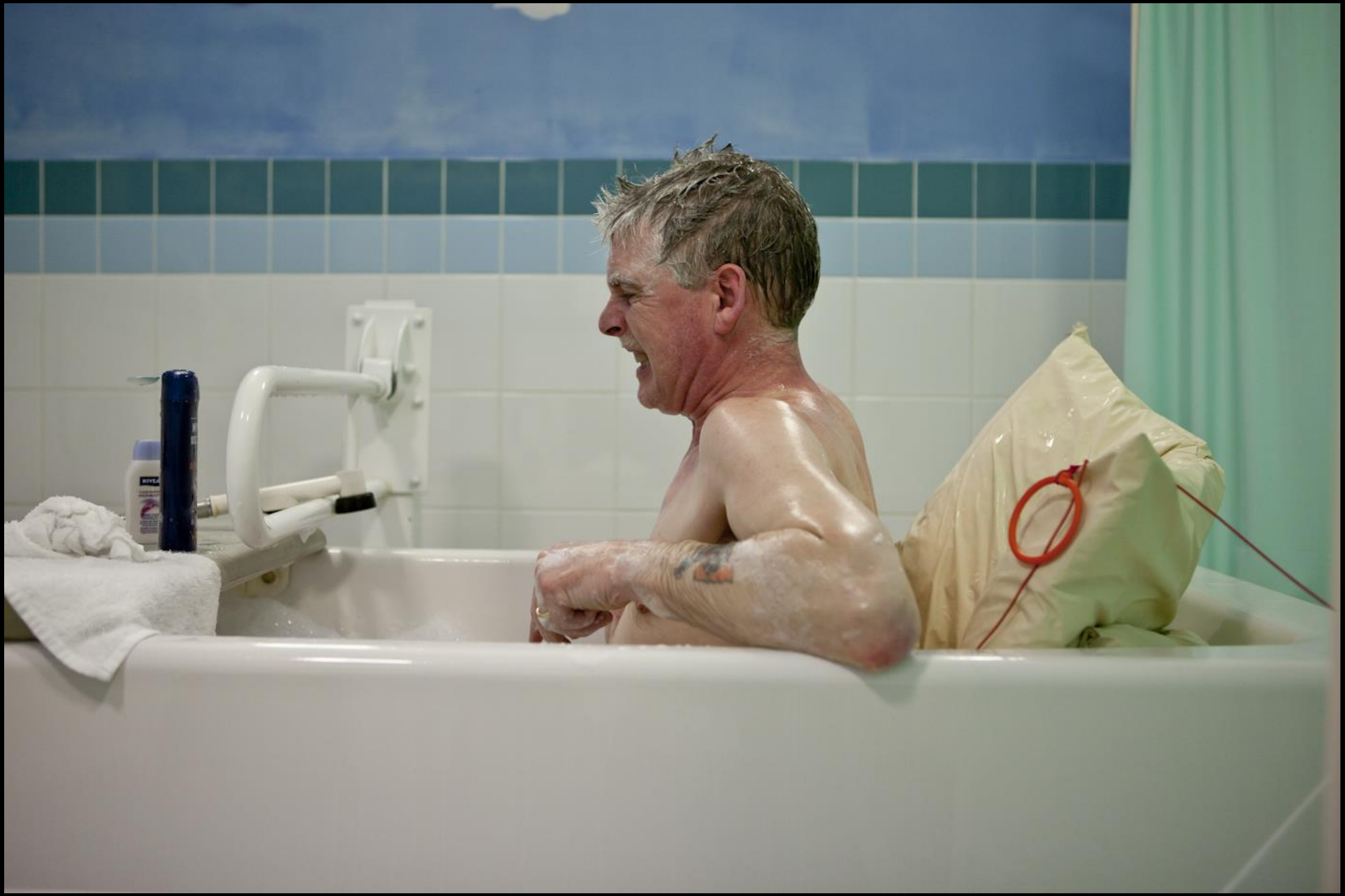

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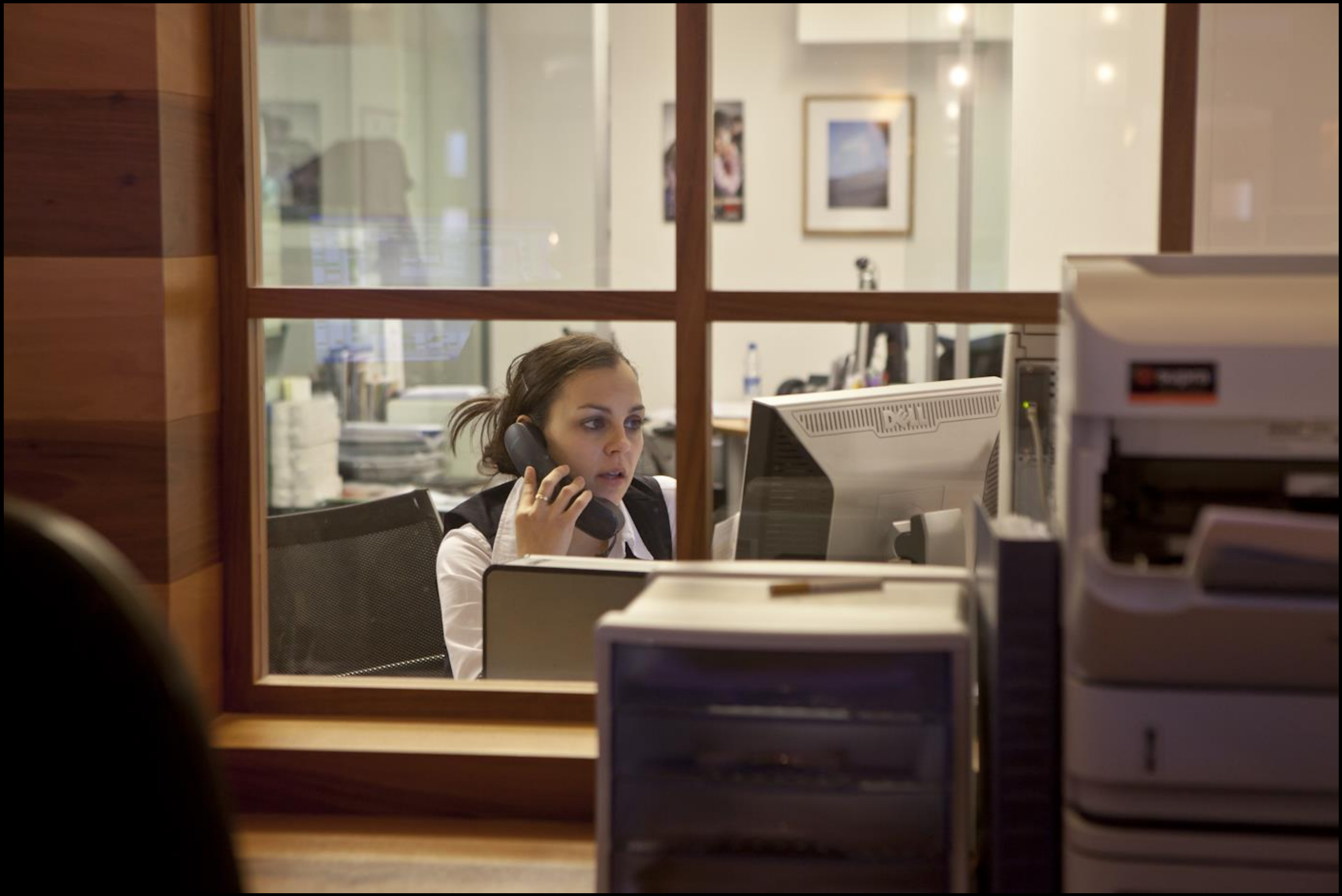

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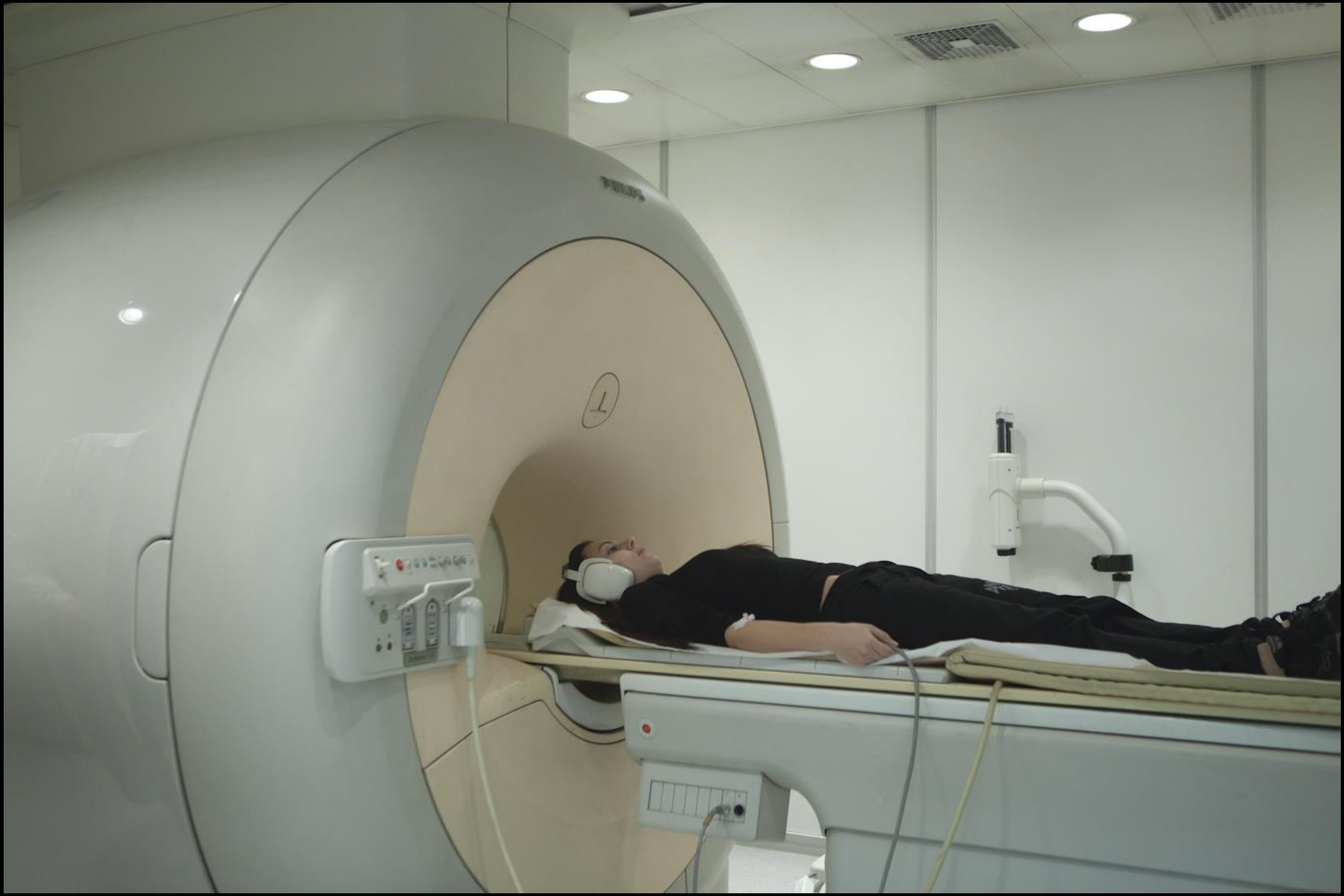

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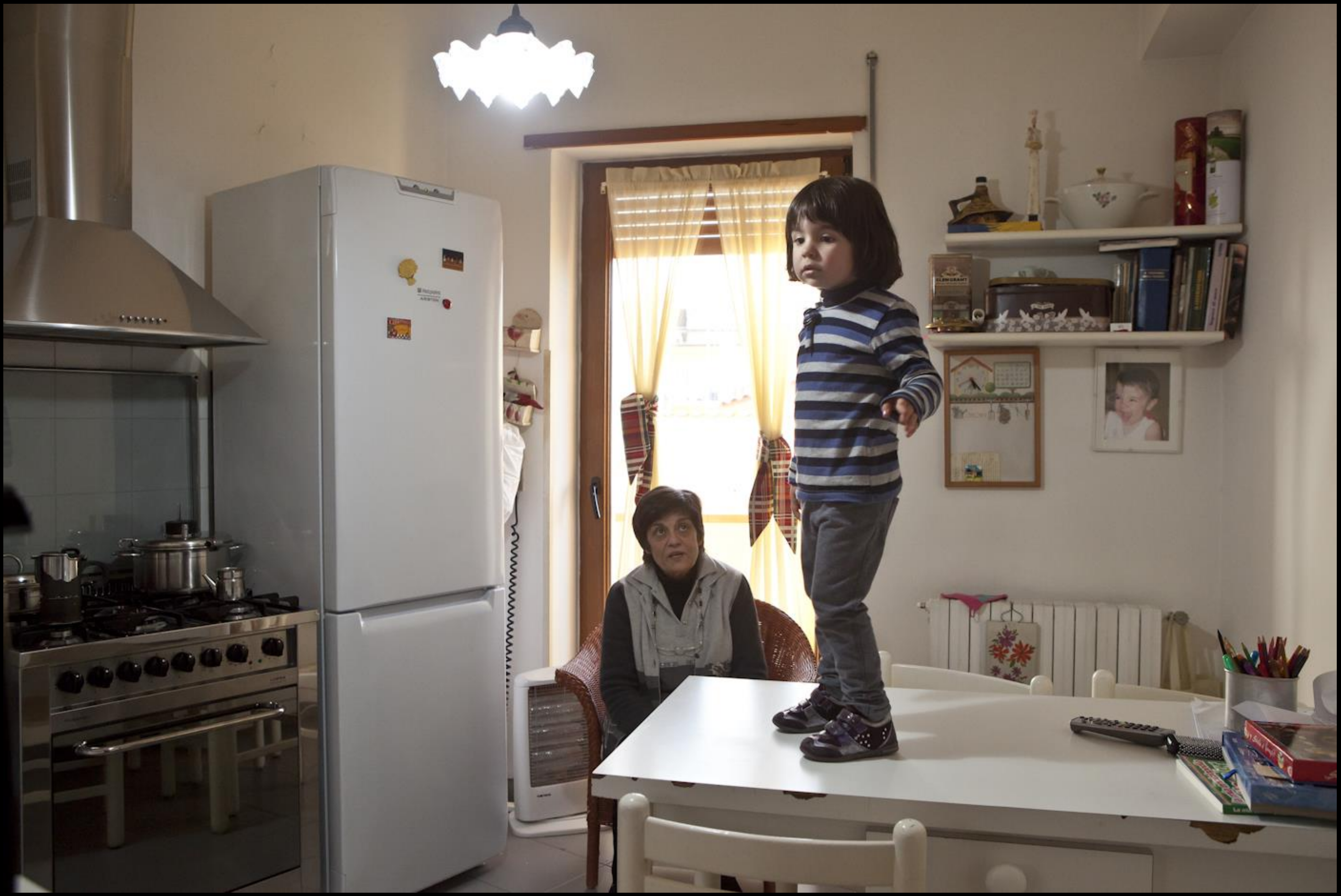

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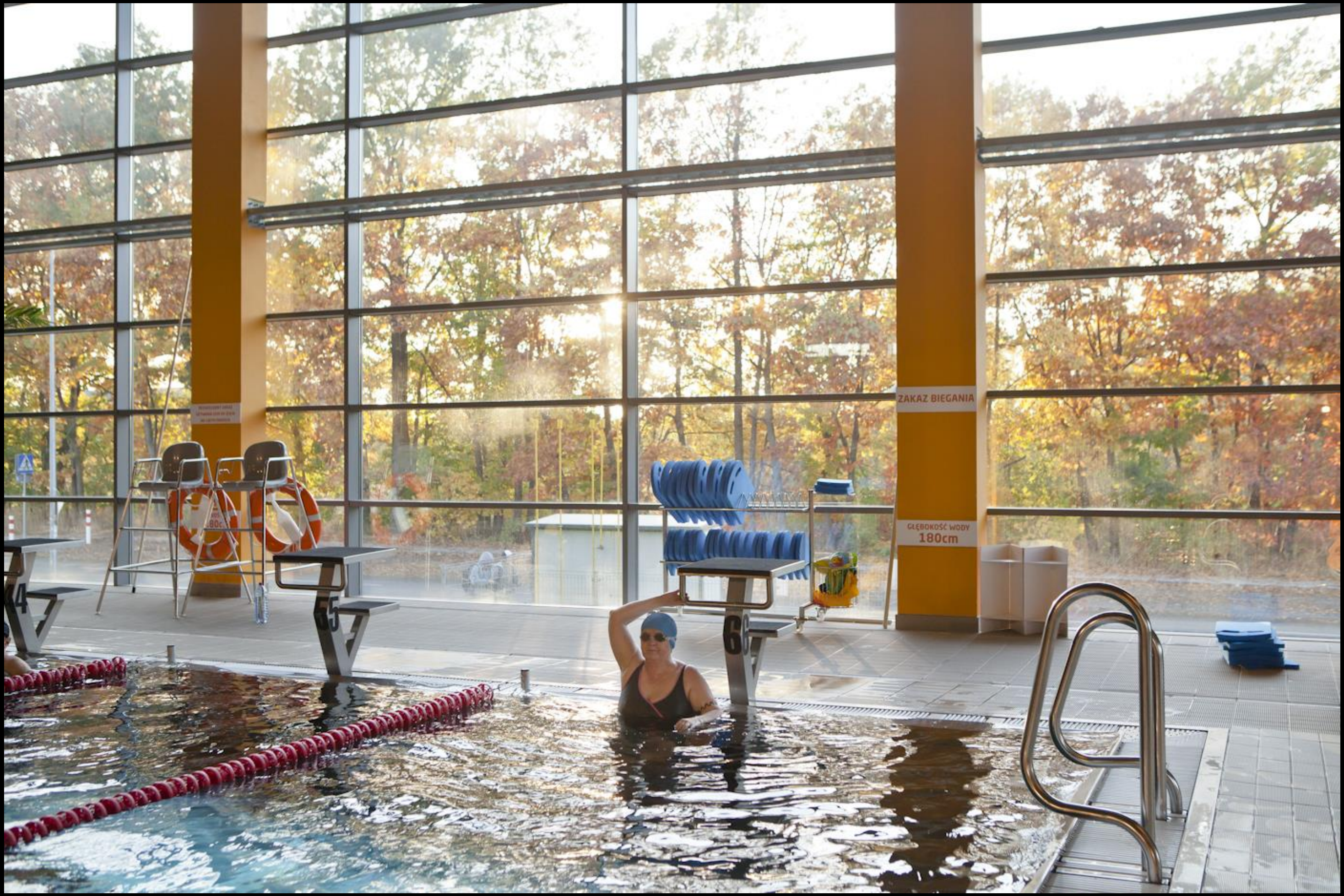

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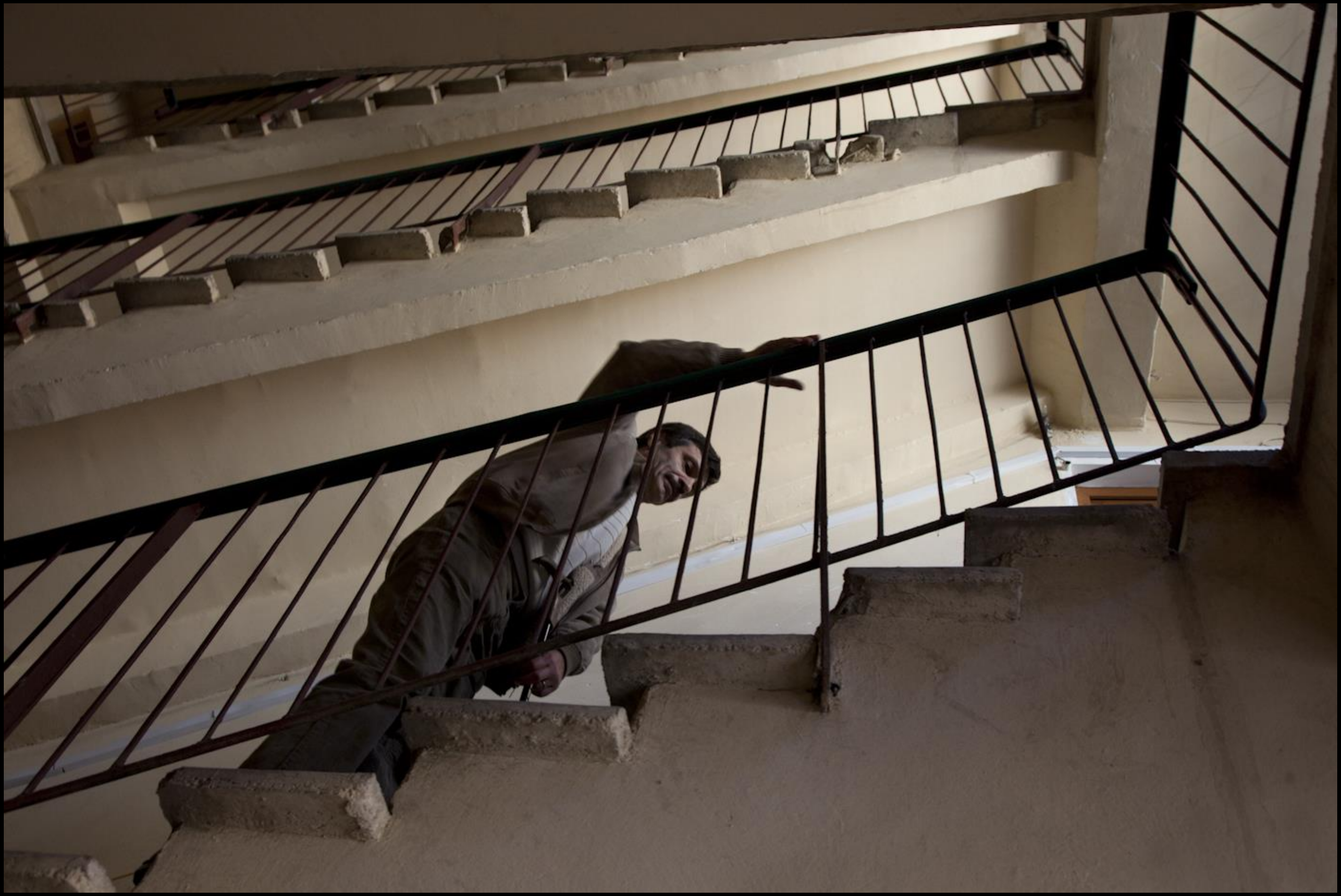

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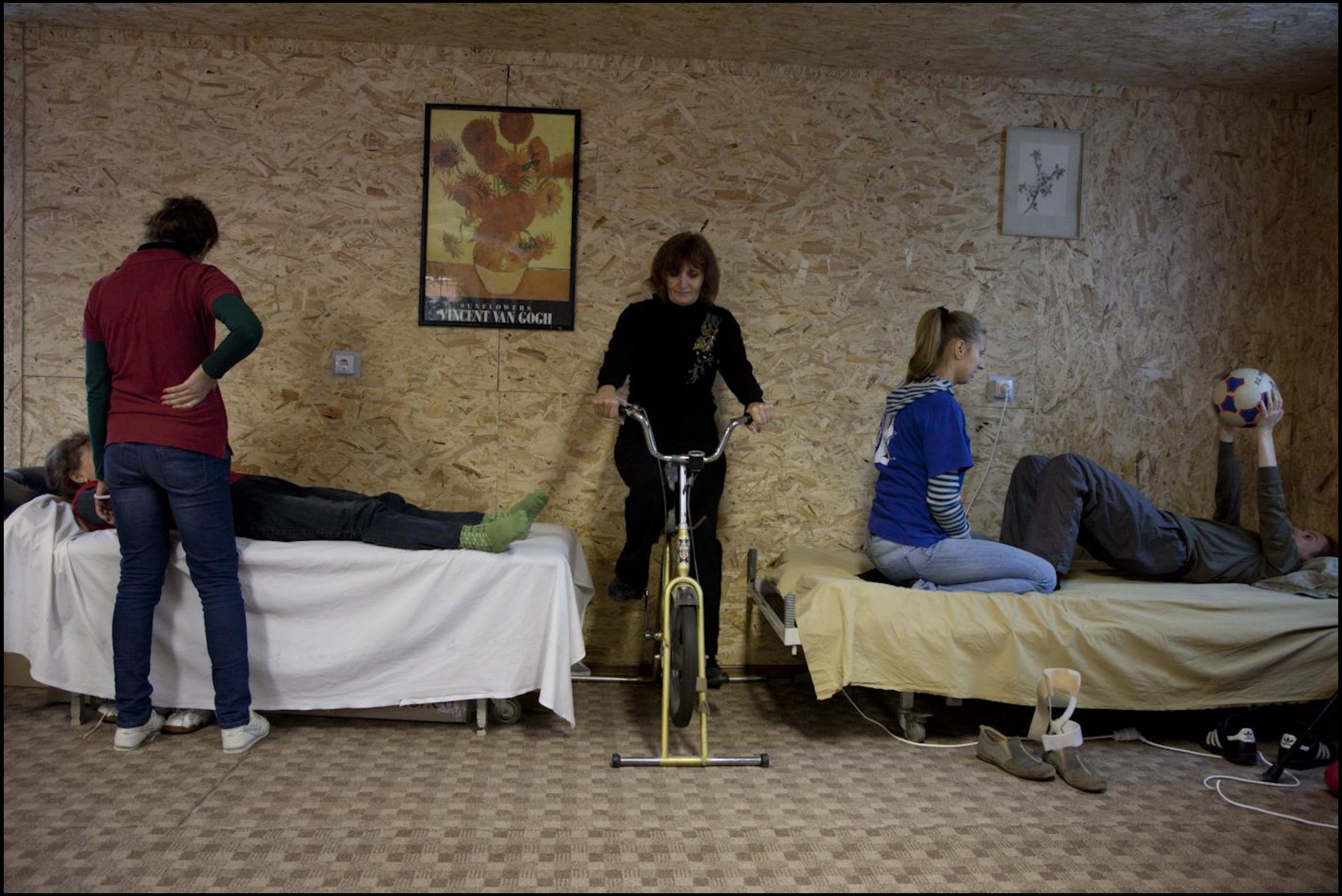

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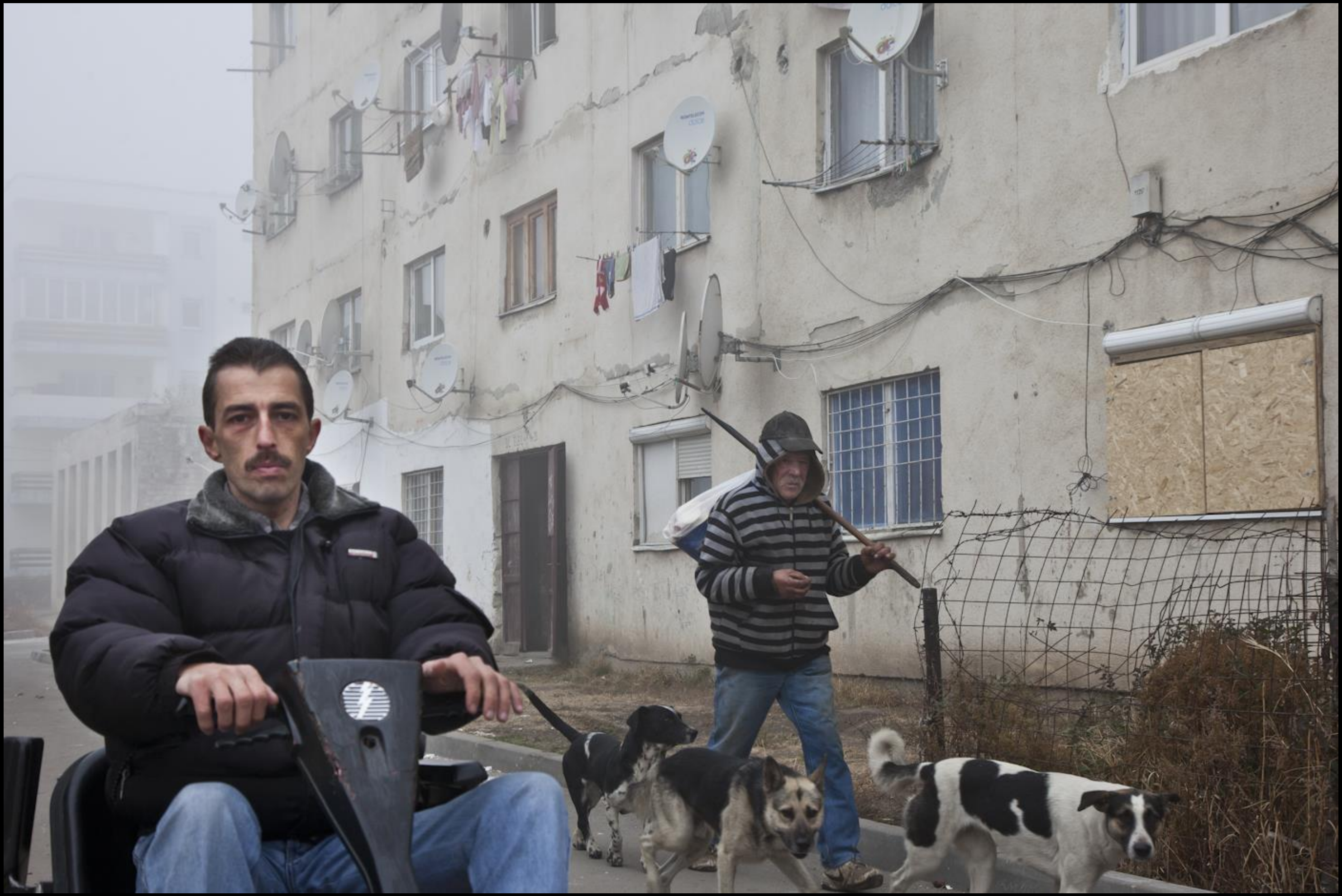

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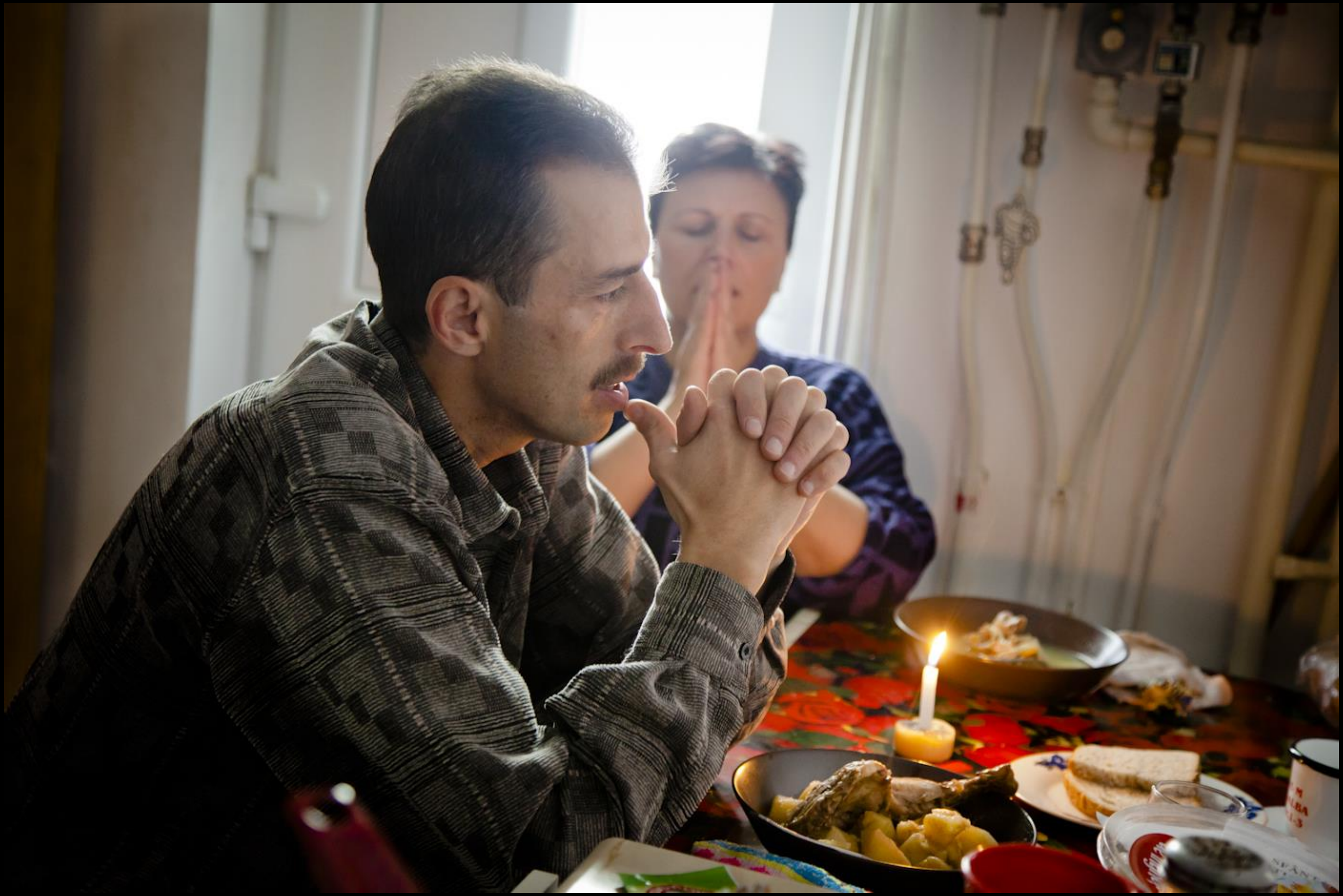

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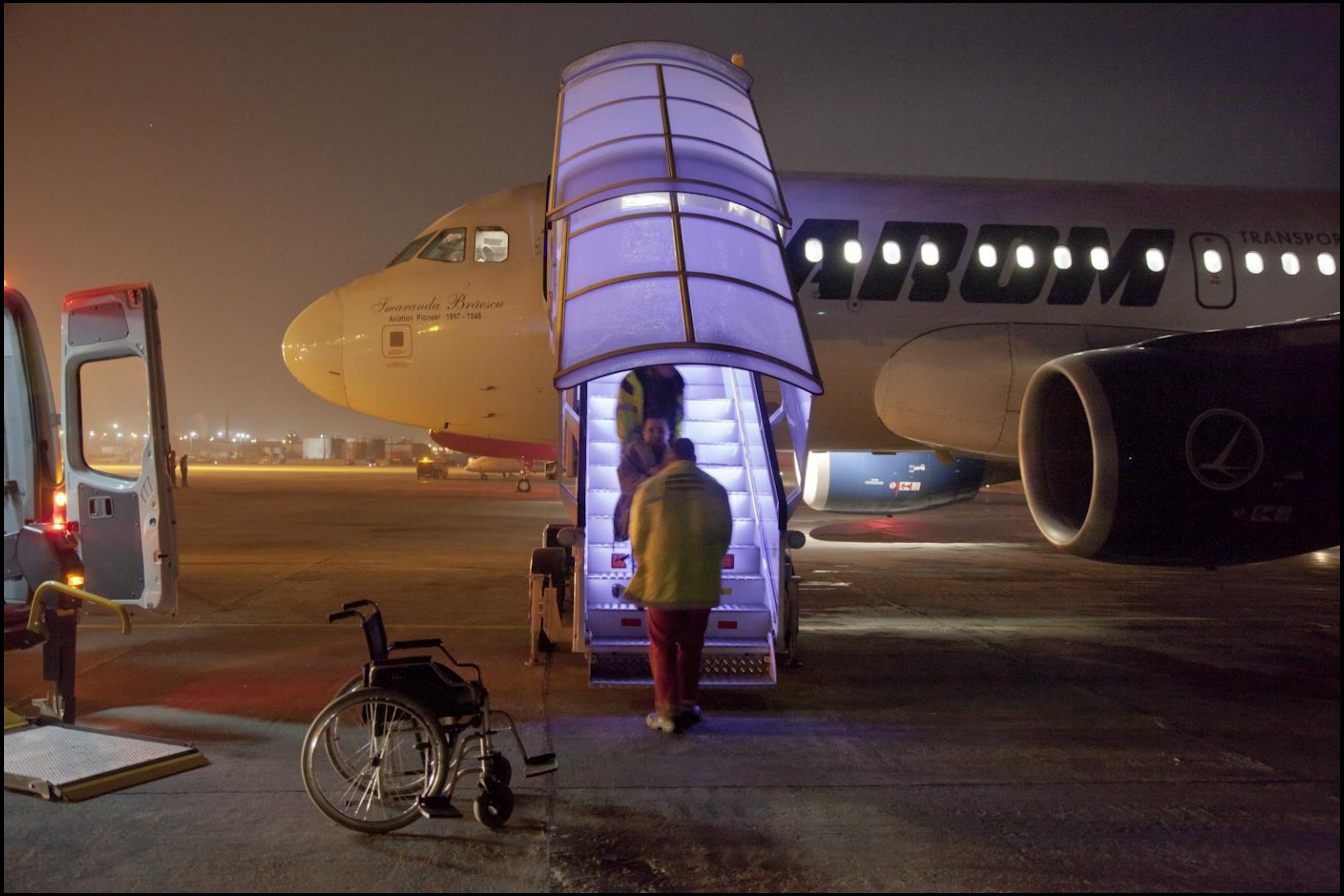

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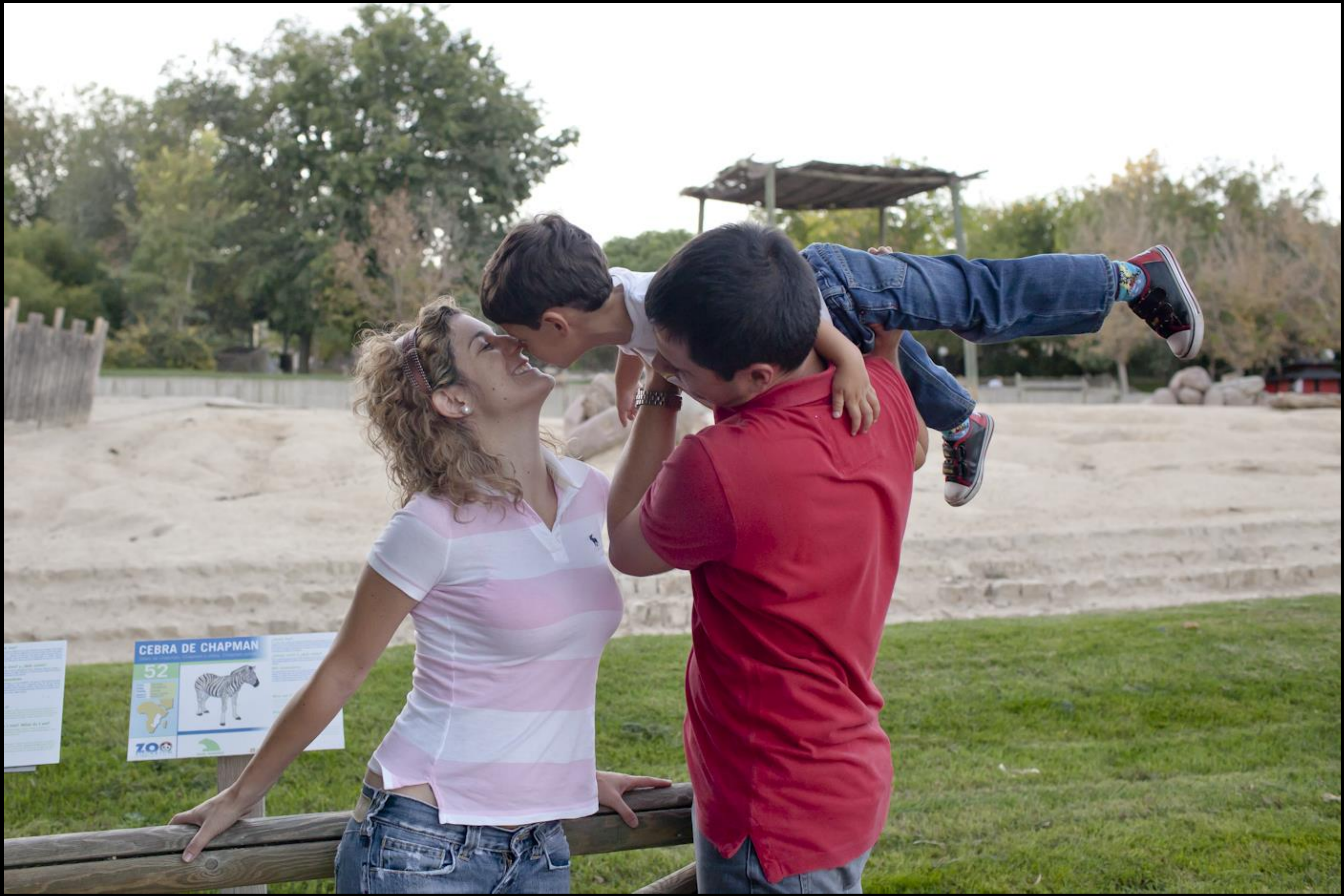

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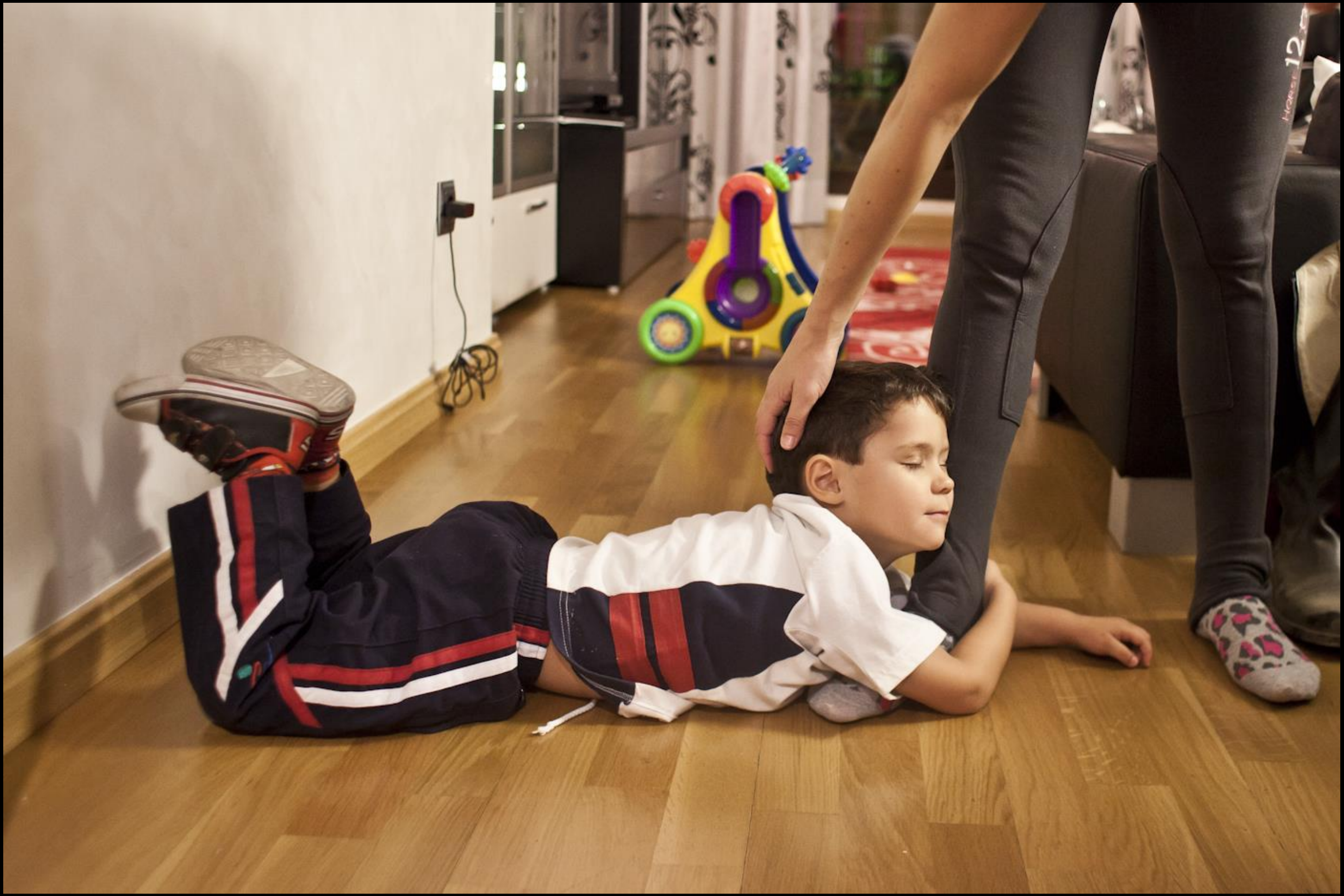

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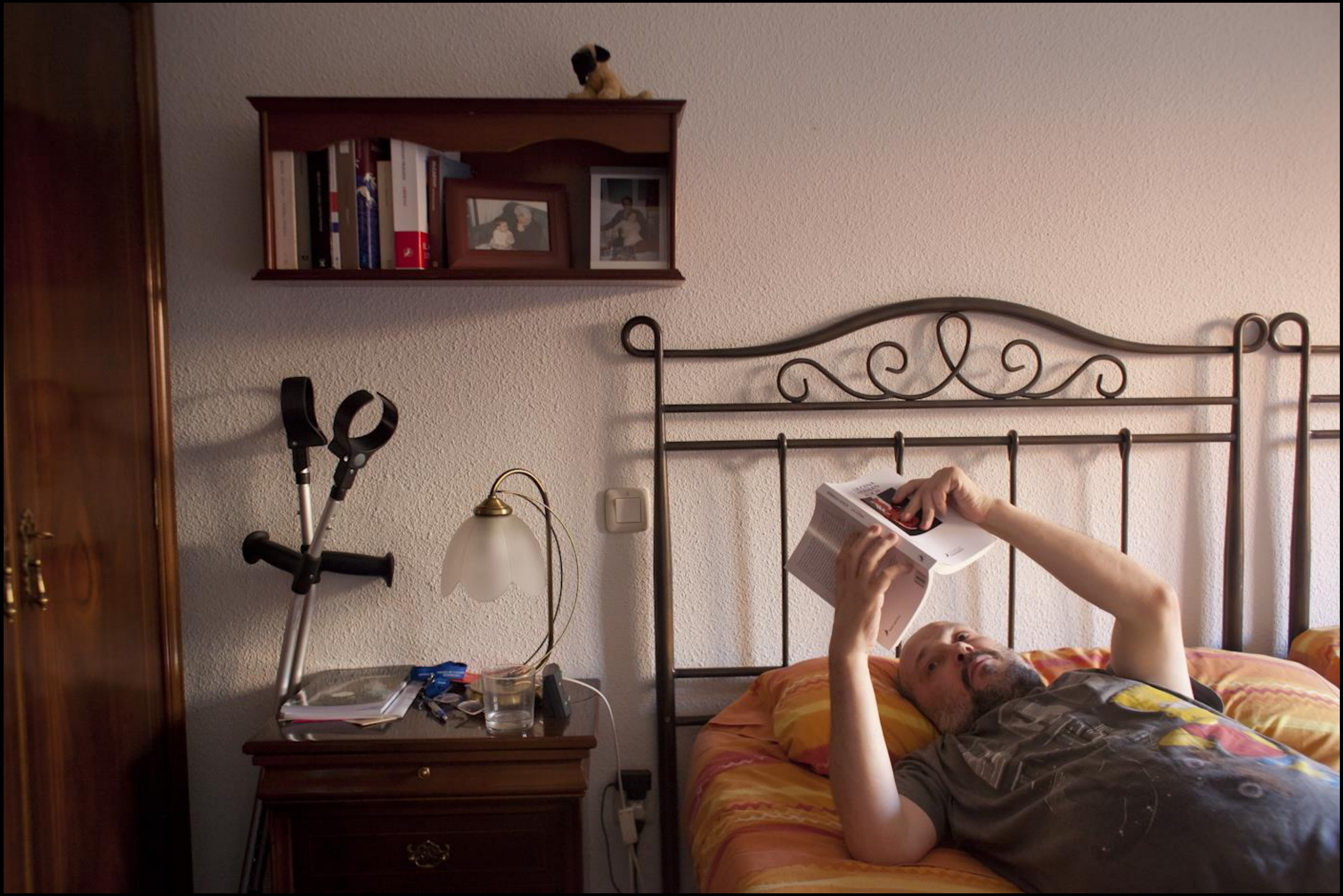

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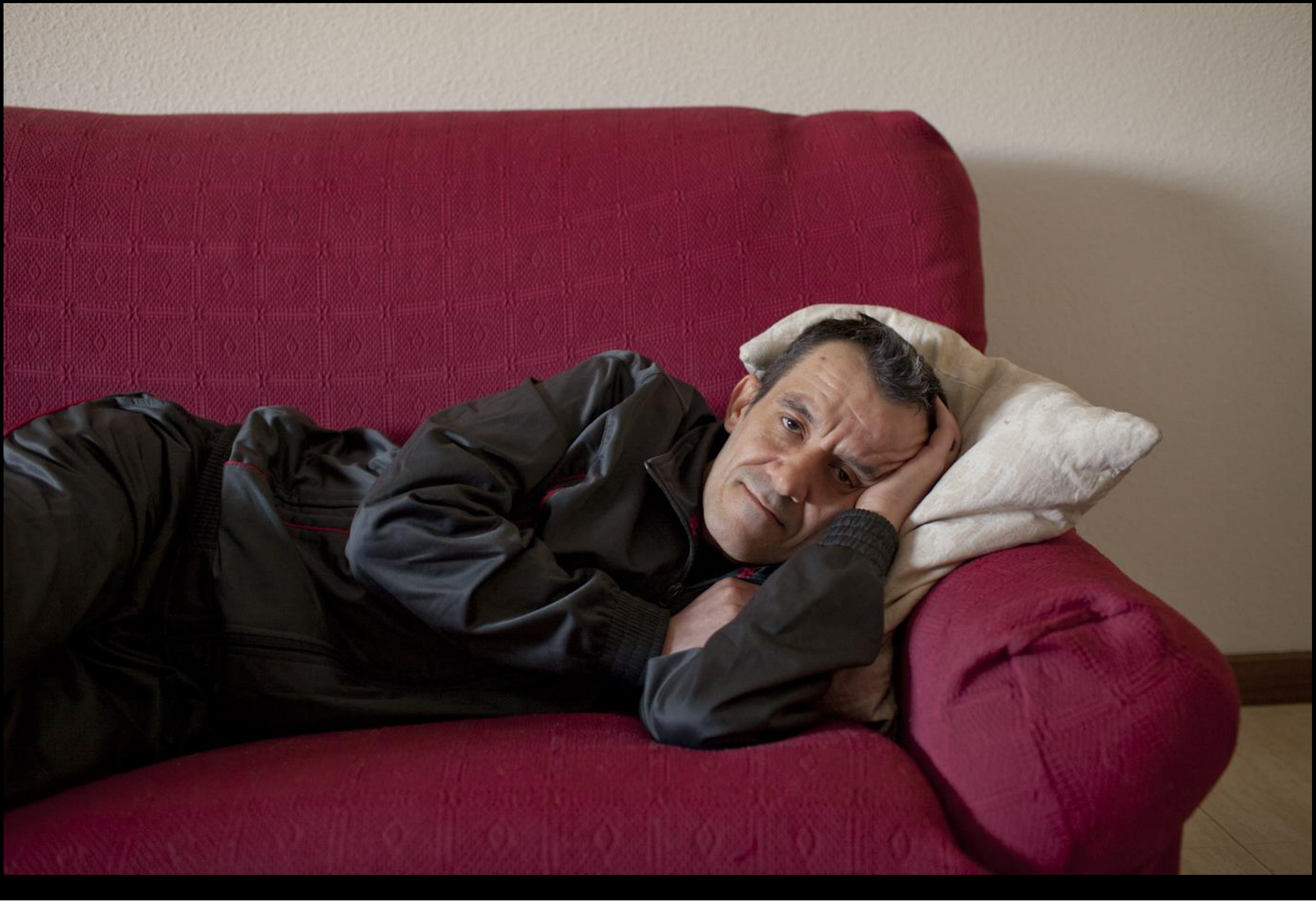

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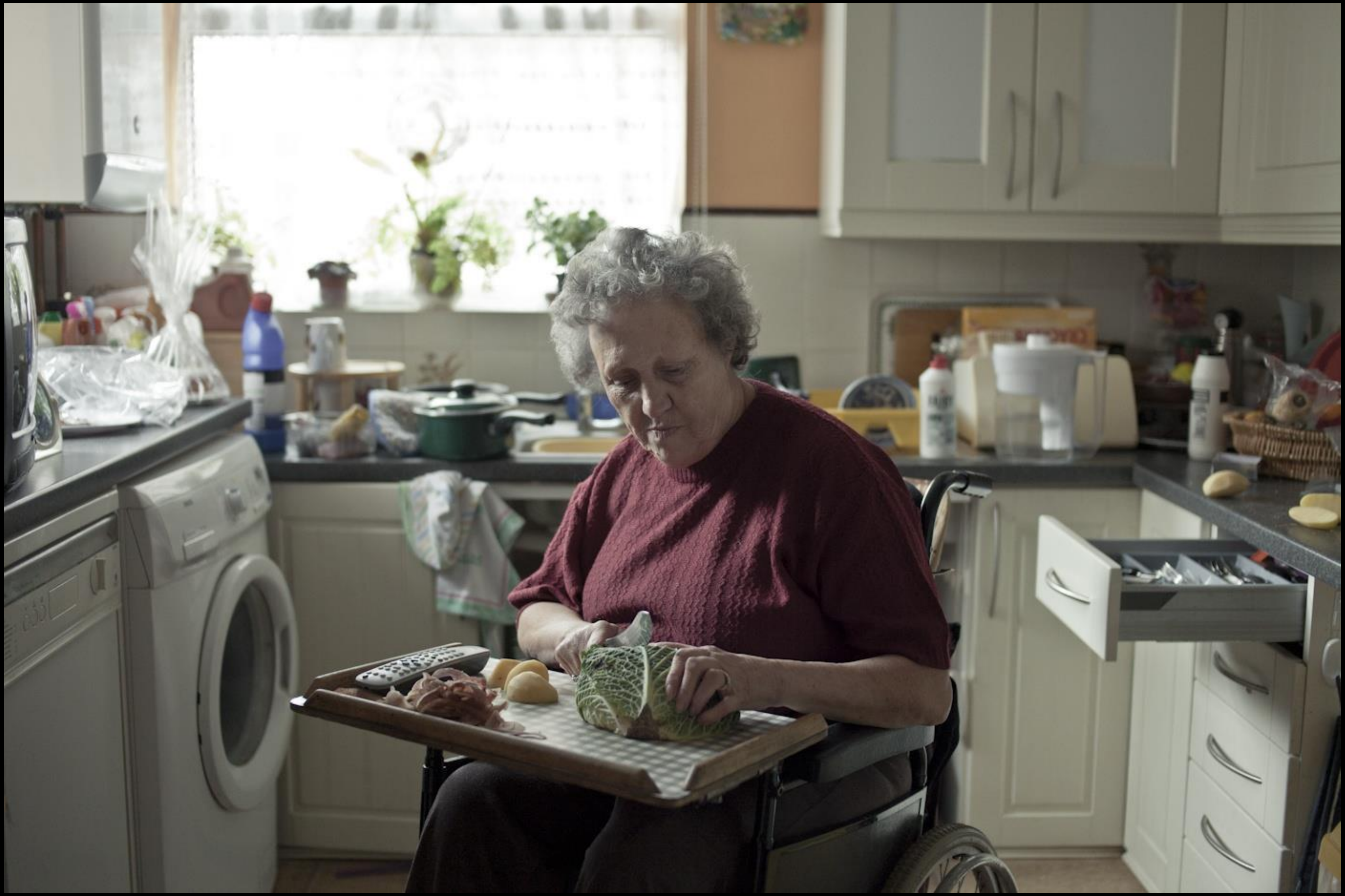

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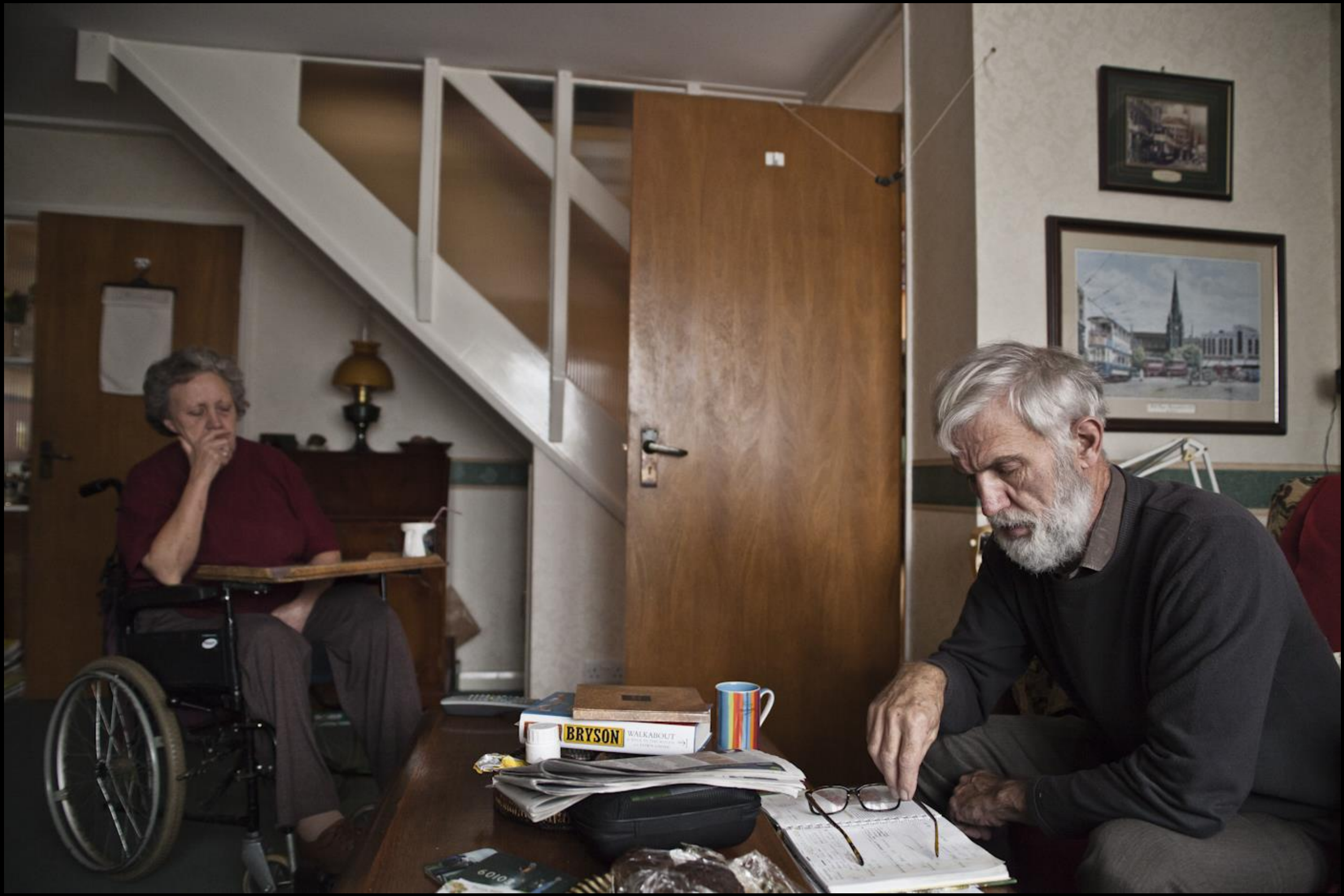

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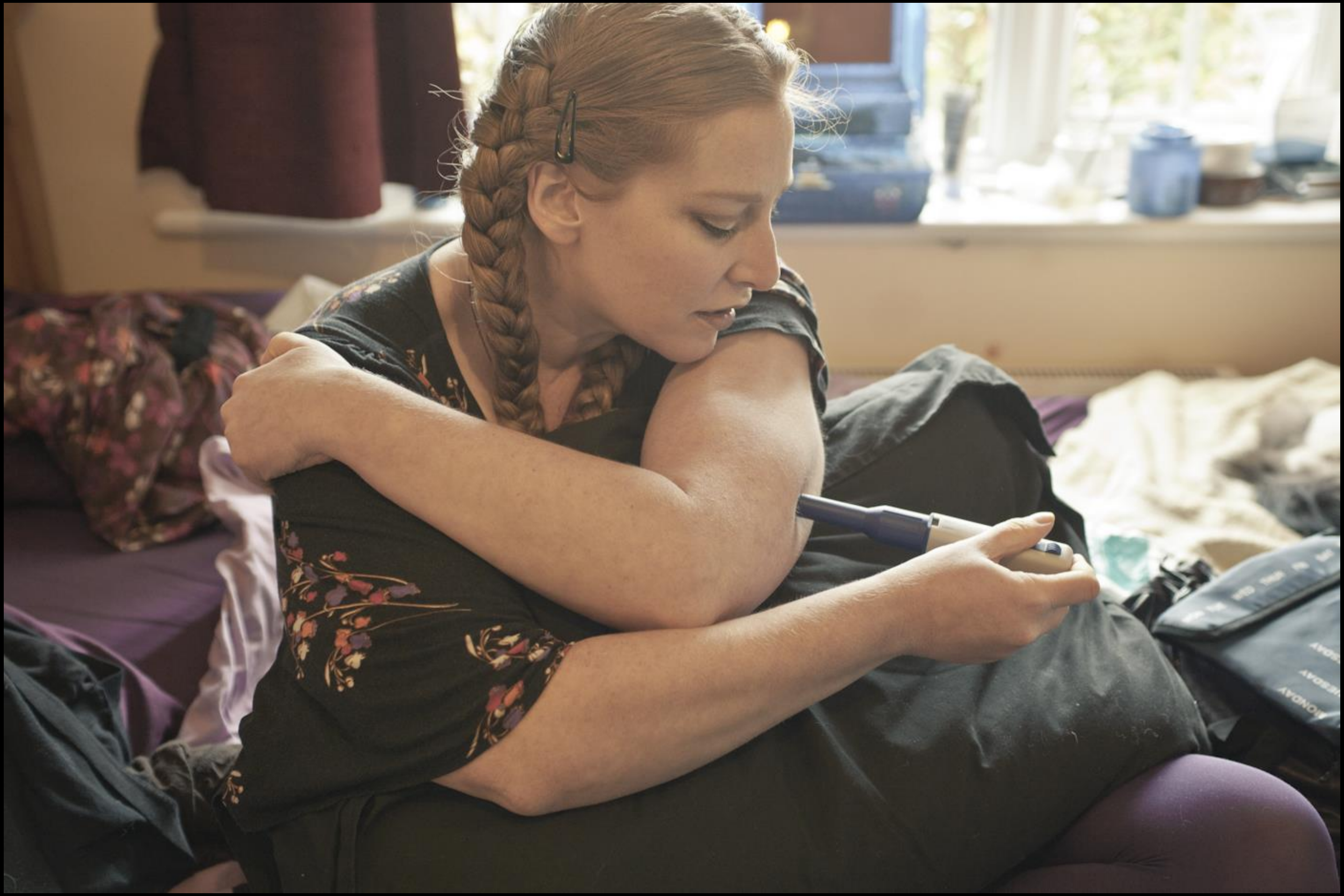

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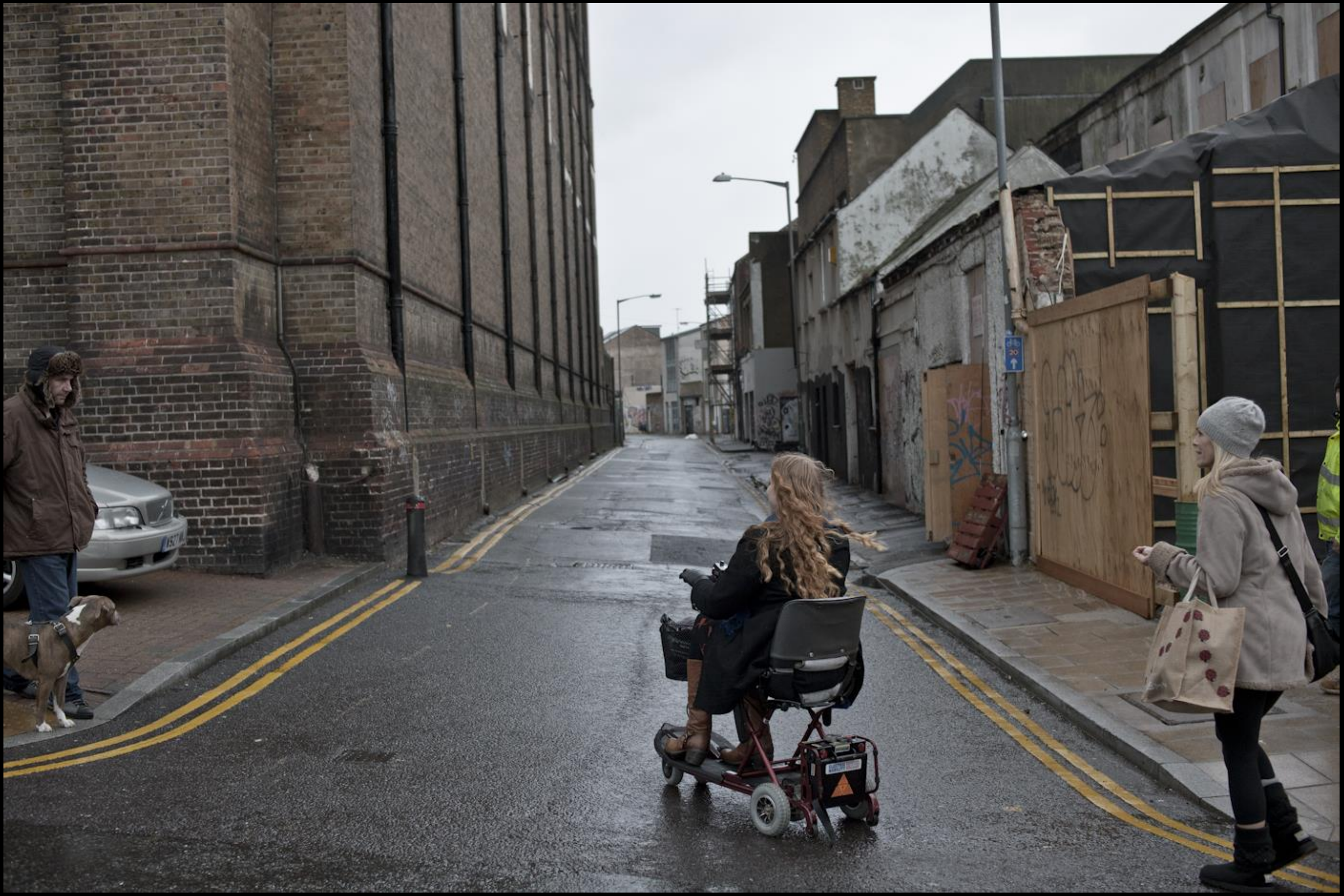

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