

CHAPTER TWO

THE POST-POLIO SYNDROME: AN ORPHAN DISEASE

Concepts and Symptoms

The Silent Years

- ▣ Re-emersion into family, work and life.
- ▣ Normalisation of the disease outcome.
- ▣ Many outside of the family never knew.
- ▣ The disease disappeared.
- ▣ Medical science , except for epidemiologists and public health physicians virtually forgot about the disease.

“How sleep the brave”

■ William Collins

- ▣ “There are no heroes of action, only heroes of renunciation and suffering. Of such there are plenty. But few of them are known, and even these not to the crowd- but to the few”.
 - Albert Schweitzer , My Life and Thought.

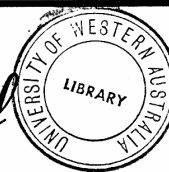
What is an Orphan?

- ▣ Form the Greek word *Orphanus* meaning bereaved.
- ▣ Bereaved; Rob, dispossess; usually of immaterial things e.g. life , hope etc.
 - Leave desolate.
- ▣ Bereaved of parent.
- ▣ Bereft of previous protection and advantages.

Why is Post-Polio an Orphan disease?

- ▣ No next-of kin. Indeed some people consider that it doesn't even exist.
- ▣ Dispossessed of any formal recognition by the modern health care system.



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PHYSICAL MEDICINE *and* REHABILITATION

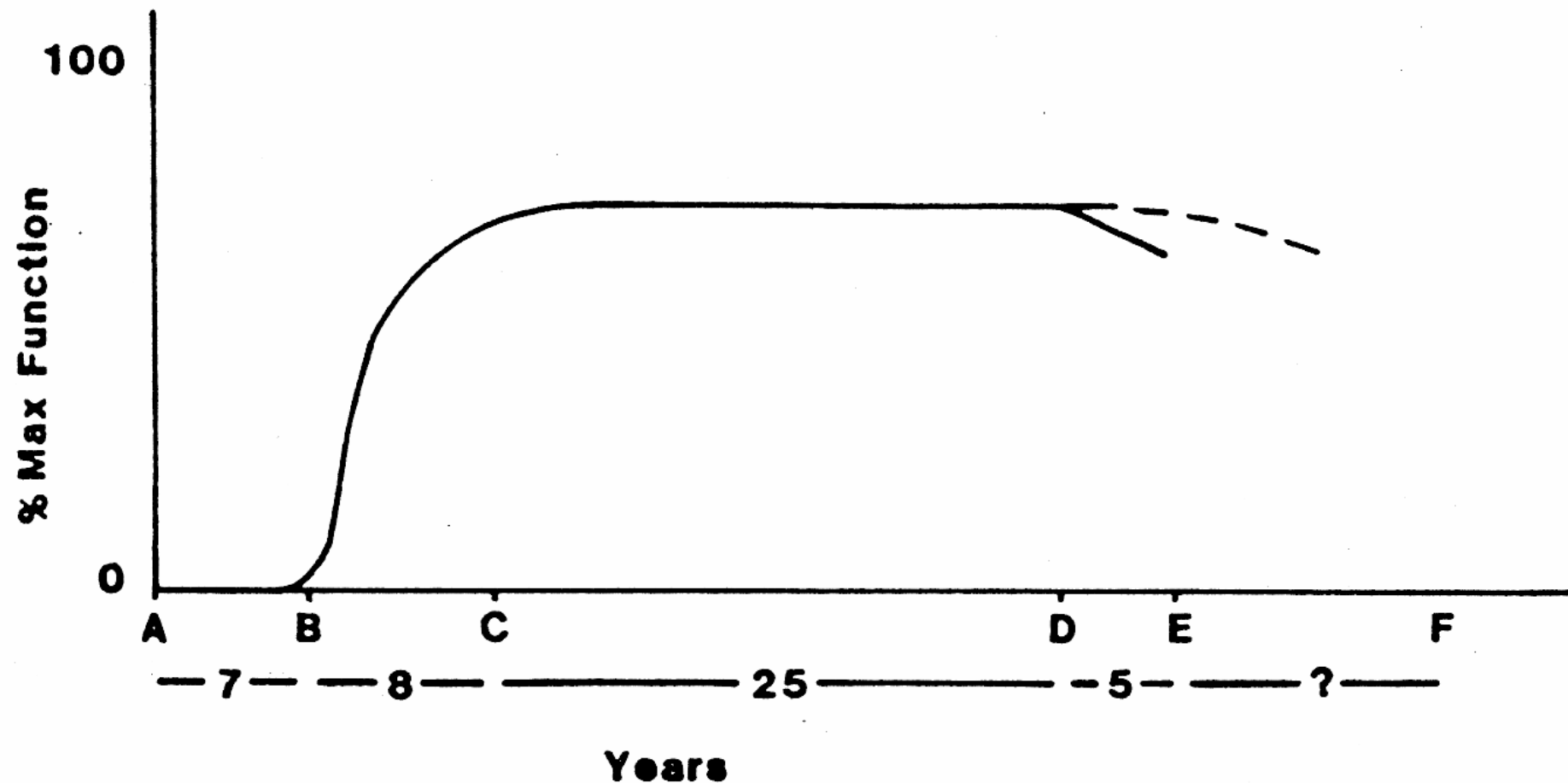
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Editor of the Month

FREDERIC J. KOTTKE, M.D.

Natural History of Poliomyelitis of Clinic Group



A Birth

B Onset of Polio

**C Maximum Neurologic
and Functional Recovery**

D Onset of New Health Problems

E Time of Evaluation

F Death

peutic interventions. A typical evaluation consisted of seven components:

- 1) A detailed medical history with special attention to current health problems as well as the extent of initial involvement from polio, the period of recovery, the duration of neurologic and functional stability, and the time of onset of new health problems;
- 2) A physical exam with special emphasis on assessing the musculoskeletal and nervous systems;
- 3) An electromyogram (EMG) and nerve conduction study of selected muscles and nerves;
- 4) A biomechanical and functional evaluation with special attention to orthotic and adaptive equipment needs;
- 5) A basic panel of screening laboratory tests that were supplemented with additional x rays and laboratory studies as indicated by the history and physical examination;
- 6) A psychosocial assessment; and
- 7) Referral to other members of the rehabilitation team or other medical specialists as needed.