

Information for you

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Epilepsy in pregnancy

About this information

This information is for you if you have epilepsy and want to know more about epilepsy in pregnancy. It may also be helpful if you are a partner, relative or friend of someone who has epilepsy and is pregnant or planning a pregnancy.

The information here aims to help you better understand your health and your options for treatment and care. Your healthcare team is there to support you in making decisions that are right for you. They can help by discussing your situation with you and answering your questions.

A glossary of all medical terms is available on the RCOG website at: www.rcog.org.uk/en/patients/medical-terms.

Key points

- Most women who have epilepsy do not have a seizure during pregnancy and have healthy pregnancies and healthy babies.
- If you are planning a baby, let your GP or epilepsy specialist know. They will review your
 medication and discuss with you the best way to prepare for a pregnancy. This will include taking
 folic acid at the higher dose of 5 mg daily.
- A specialist team will look after you and your baby during pregnancy.
- You must not stop or change your epilepsy medication unless so advised.
- You should be able to have a vaginal birth.
- You are at increased risk of having seizures during labour and after birth. Taking your medication regularly and getting enough rest lowers this risk.
- Breastfeeding is safe even if you are taking epilepsy medication.



What does having epilepsy mean for me and my baby?

Epilepsy is a relatively common condition. Most women who have epilepsy remain free of seizures throughout pregnancy and they have straightforward pregnancies and healthy babies. It is important to continue taking your medication because having frequent seizures during pregnancy can be harmful for you and your baby. Therefore, planning your pregnancy and having extra care during your pregnancy can reduce the risks to you and your baby.

For me

Some women with epilepsy may have more seizures when they are pregnant. This is usually because they have stopped taking their medication, or are not taking it regularly. Pregnancy itself or tiredness can also increase the number of seizures. If this happens to you, you should consult your healthcare professional.

There are different types of seizures and your doctor should give you information on the type of epilepsy you have and possible effects on you and your baby. Most types of epilepsy will not cause any harm to you or your baby. Medications for epilepsy should never be discontinued or changed without consulting your healthcare professional.

A very rare but serious complication of poorly controlled epilepsy is sudden unexplained death with epilepsy (SUDEP), which may occur more frequently in pregnancy.

For my baby

With any pregnancy there is a small chance that your baby may not develop normally in the womb. The risk of this happening may be slightly higher with certain epilepsy medications. The risk depends on the type of medication you are taking and the dosage, and it increases if you are taking more than one medication for epilepsy. The most common problems for your baby linked to these medications include spina bifida, facial cleft or heart abnormalities. Taking folic acid reduces this risk.

The epilepsy medication sodium valproate is known to cause harm to developing babies. This includes physical problems and an increased risk of developmental delay, a condition that can affect communication, language skills and behaviour. If you are taking sodium valproate your epilepsy specialist should change this to an alternative medication before you become pregnant. You should speak to them to make a plan for your pregnancy before you stop your contraception. If you become pregnant unexpectedly while taking sodium valproate do not stop the medication yourself but tell your GP and epilepsy specialist straight away so they can discuss the safest options for treatment with you.

I have epilepsy. What should I think about before becoming pregnant?

Talk to your GP

Most women with epilepsy have healthy babies. It is important that you let your GP know that you are planning to have a baby. You may be referred to a neurologist or epilepsy specialist for advice who will be able to talk to you about what pregnancy will mean in your individual situation.

They will talk to you about the medication you are on and what can be done to reduce the risks to you and your baby. You may be advised to stay on your current medication but alter the dose. Sometimes you may be advised to change your medication. Changing the medication or its dose may affect your ability to drive.

Although it is not needed routinely, sometimes your healthcare professional will arrange for blood tests to measure the level of the medication before altering the dose.

Start taking folic acid at the higher dose of 5 mg daily

All pregnant women are advised to take folic acid as it helps to reduce the risk of their baby having spina bifida. It may also reduce the risk of heart or limb defects. Your doctor will advise you to take a daily dose of 5 mg of folic acid. This is higher than usual and will need to be prescribed for you. This higher dose is needed because of your epilepsy medication, which can increase the risk of your baby being born with spina bifida.

If you are planning to have a baby, it is worth continuing contraception until you have seen a neurologist or epilepsy specialist and have taken folic acid for 3 months. Your GP or family planning service can advise you on which contraception is best for you if you are unsure.

As most of your baby's development takes place in the first 3 months of pregnancy, you should ideally be taking folic acid for 3 months before you conceive and continue to take it until you reach your 13th week of pregnancy.

I was not planning a baby but I have found out I am pregnant

- Do not stop your medication. Most epilepsy medication itself only carries a small risk to your baby, whereas stopping your medication could pose a serious risk to both you and your baby. Talk to your GP or epilepsy nurse as soon as possible. They will arrange for you to see an obstetrician or neurologist who will be able to give you advice.
- If you are not taking folic acid already, you should start taking it now. You should take the higher dose of 5 mg daily. See your GP, who will prescribe this for you.

If nausea or vomiting makes it difficult to keep your epilepsy medication down, talk to your GP, midwife or epilepsy specialist.

What extra care will I need during pregnancy?

Your midwife will refer you for a hospital antenatal clinic appointment early in your pregnancy. You will be under the care of a specialist healthcare team, which will usually include an obstetrician, a midwife and a specialist healthcare professional.

At your first visit you will be given information about:

- ways to reduce the risk of having seizures, for example by making sure that you take your medication and by trying to get as much sleep/rest as possible
- the UK Epilepsy and Pregnancy Register. This was set up in 1996 to collect information about the epilepsy medication that women take during pregnancy and the health of their babies. It also gives advice about epilepsy medication(s) taken during pregnancy. You will be invited to join the Register. You can also contact the Register directly on Freephone 0800 3891248.

Having epilepsy will usually mean more clinic visits at the hospital. Your team will discuss your general health with you, and whether you have had any seizures recently. You may be advised to increase or alter your medication if the number of seizures you are having has increased.

Like all pregnant women, you will be offered routine ultrasound scans to check how your baby is developing. This includes checking your baby's spine and heart. You may be offered additional scans to monitor the growth of your baby if you are taking medication for epilepsy.

Taking your medication as advised and extra precautions such as taking showers rather than baths can reduce your risk of any accidents such as drowning.

Where should I have my baby?

You will be advised to give birth in a consultant-led maternity unit with a special care baby unit so that you and your baby can get extra care if needed.

Will I need to have my baby early?

Having epilepsy, particularly if it is well controlled, is not by itself a reason to need to give birth early.

How will I have my baby?

You will be able to discuss your birth plan with your midwife and obstetrician. Most women with epilepsy are able to have a vaginal birth. Epilepsy on its own does not require a planned caesarean section or induction of labour. If you would like to have a water birth, you should discuss this with the team looking after you.

What happens in labour?

The risk of having a seizure during labour is very small, especially if your epilepsy is well controlled. However, being tired, dehydrated and in pain can increase the risk, so make sure that you have as much support, rest and pain relief as possible.

You should bring your epilepsy medication to hospital with you and take it as you normally would during your labour.

Gas and air, TENS machines and an epidural are all suitable for pain relief. Injections of a strong pain reliever such as diamorphine can also be used. Pethidine (another type of pain relief) is not recommended, because in high doses it has been linked with seizures.

What happens after my baby is born?

Your baby will usually stay with you unless they need extra care.

Vitamin K

You will be offered an injection of vitamin K for your baby. Vitamin K is needed for blood to clot properly. Levels are low in all newborn babies, which puts them at risk of bleeding. Some anti-epileptic medication can further lower vitamin K levels.

Seizures

You may have more seizures after giving birth because of tiredness, stress and anxiety. Get as much rest and help with your baby as you can.

Medication

Missing medication also increases the risk of seizures. Forgetting to take medication after your baby is born is very common. Some women set an alarm on their phone or use an app to help them remember to take their medication on time.

If you have been taking more medication during your pregnancy, you may be able to go back to your previous dose. Talk to your specialist healthcare professional before your baby is born so that you have a plan in place.

Advice to keep your baby safe

Your midwife and epilepsy nurse will talk to you about ways of keeping your baby safe if you have a seizure, including:

- getting plenty of help and rest
- using very shallow baby baths
- nursing your baby on the floor
- laying your baby down if you have a warning aura.

Contraception

It is a good idea to have a plan for contraception. You can discuss this with your healthcare professional before you leave hospital.

Can I breastfeed my baby?

How you choose to feed your baby is a very personal decision. There are many benefits of breastfeeding for you and your baby. Epilepsy medication can pass into breast milk but the amount is usually so small that it is not harmful. Breastfeeding is considered safe even if you are taking epilepsy medication.

Making a choice

Shared Decision Making

If you are asked to make a choice, you may have lots of questions that you want to ask. You may also want to talk over your options with your family or friends. It can help to write a list of the questions you want answered and take it to your appointment.



Ask 3 Questions

To begin with, try to make sure you get the answers to three key questions if you are asked to make a choice about your healthcare.

- 1. What are my options?
- 2. What are the pros and cons of each option for me?
- 3. How do I get support to help me make a decision that is right for me?

Ask 3 Questions is based on Shepherd HL, et al. Three questions that patients can ask to improve the quality of information physicians give about treatment options: A cross-over trial. Patient Education and Counselling, 2011;84: 379-85







www.aquanw.nhs.uk

Further information

Epilepsy Action: Epilepsy and having a baby www.epilepsy.org.uk/info/women/having-baby

Epilepsy Society: Pregnancy and parenting www.epilepsysociety.org.uk/pregnancy-and-parenting

UK Epilepsy and Pregnancy Register www.epilepsyandpregnancy.co.uk

Sources and acknowledgements

This information has been developed by the RCOG Patient Information Committee. It is based on the RCOG Green-top Clinical Guideline *Epilepsy in Pregnancy*, which contains a full list of the sources of evidence we have used. You can find it online at: www.rcog.org.uk/en/guidelines-research-services/guidelines/gtg68.

This leaflet was reviewed before publication by women attending clinics at the Royal Victoria Infirmary, Whipps Cross University Hospital, Wrexham Maelor Hospital, Raigmore Hospital, St Thomas' Hospital, St Mary's Hospital, St Bartholomew's Hospital, Royal London Hospital, Birmingham Women's Hospital, University Hospital Birmingham and Birmingham and Solihull Mental Health NHS Foundation Trust, by the RCOG Women's Network and by the RCOG Women's Voices Involvement Panel.

Maternity epilepsy shared-care toolkit

Formulated to encourage joint working with women to optimise holistic healthcare

| My full name | |
|------------------|--|
| Date of birth | |
| NHS Number | |
| Hospital Number | |
| Name of hospital | |



This toolkit is designed to provide a summary of your epilepsy, treatment and management recommendations. It should be stored securely in your maternity hand-held notes. A copy should be provided for you to keep after you are discharged from hospital following birth.

Please encourage all members of your multi-professional team to write in and refer to this toolkit during your pregnancy, labour and after you have had your baby. Please ask them to date and sign each written entry they make and click on the links to download further information. This toolkit is designed to be used alongside RCOG green-top guidelines & www.womenwithepilepsy.co.uk

Your multi-professional team emergency contact details

| Name | Title | Telephone | Email/FAX |
|------|------------------------------|-----------|-----------|
| | GP | | |
| | Community Midwife | | |
| | Obstetrician | | |
| | Neurologist | | |
| | Epilepsy Specialist Nurse | | |
| | Health visitor | | |
| | Pharmacist | | |
| | | | |
| | | | |

GP/Midwife complete this page at first antenatal booking appointment

Women with history of seizures or epilepsy, fast-track urgent multi-professional referral to consultant neurologist/epilepsy specialist, consultant obstetrician/physician

Answer: yes or no

| * | Seizures in last twelve months (active epilepsy) | Yes/No |
|----|---|--------|
| * | Epilepsy medicine stopped with or without medical advice in last year | Yes/No |
| ** | Seizures never controlled with epilepsy medicines | Yes/No |
| * | History of status epilepticus/prolonged seizures | Yes/No |
| * | History of seizures from sleep (tonic clonic) seizures | Yes/No |
| * | Focal epilepsy (with or without bi-lateral tonic clonic seizures) | Yes/No |
| * | More than one epilepsy medicine is prescribed | Yes/No |
| * | Active epilepsy during previous pregnancy | Yes/No |
| * | Women with limited English language | Yes/No |
| * | Diagnosis is uncertain | Yes/No |
| * | History of substance misuse (including alcohol) | Yes/No |
| * | History of brain surgery, lesion, stroke or head injury | Yes/No |
| * | Learning/intellectual disability | Yes/No |
| * | History of non epileptic attack disorder | Yes/No |
| * | Complex physical, mental or social co-morbidities | Yes/No |

Ask the following information about epilepsy medication

| Medicine name | Dose taken | What time(s) do you take it? | Total daily dose |
|---------------|------------|------------------------------|------------------|
| | | | |
| | | | |
| | | | |
| | | | |

Other medication prescribed/over the counter:

Has folic acid been started? Yes/No Dosage: 5mg /400mcg Date started:

If higher dose folic acid (5mg) not prescribed, contact GP for individual prescribing advice in pregnancy

Allergies: Yes/No Further details

Other health conditions:

Seizure characteristics: woman to complete; she may need to gain information from witness

Generalised: Yes/No Focal (partial): Yes/No Unclassified/Unknown: Yes/No

How many seizures in last twelve months?

Approx. date/time of day of last three seizures:

Is there a warning before seizure (aura): Yes/No

Awareness lost: Yes/No

Seizure witnessed: Yes/No

What happens?

How long do they last?

Tongue bitten: Yes/No

Symptoms following seizure:

How long to recover?

Seizure diary: Yes/No Please ask woman to maintain pregnancy seizure diary (page 6)

| Details of www.womenwithepilepsy.co.uk website Information booklet: Epilepsy Action pregnancy & having a baby RCOG information leaflet: Epilepsy in pregnancy Provide safety advice to optimise well-being: advise shower rather than bath (leave door unlocked). Avoid Jacuzzis & hot tubs & inform the lifeguard about epilepsy/swim with a buddy in a pool. Extreme caution near water's edge (including the bath) to reduce risk of drowning if unexpected seizure occurs at home or in hospital. Information leaflets: Epilepsy Action safety & Caring for baby Encourage women to download: EpSMon epilepsy self-monitoring app First aid advice for partner Epilepsy Action First Aid Where possible, please advise women with epilepsy not to sleep alone Stress importance adherence with epilepsy medication; not taking medication is a leading cause seizure recurrence. Treatment advice Is vomiting affecting absorption/adherence of epilepsy medication? Advise women seek urgent advice from medical/neurology/obstetric team Issue UK Epilepsy & pregnancy registration forms Issue UK Epilepsy & pregnancy registration forms encouraged before 20 week anomaly scan or call 0800 3891248 to register. Women taking sodium valproate, provide Valproate Patient Booklet & patient letter NHS England Discuss information from MHRA: Epilepsy in pregnancy leaflet Lion: multi-professional team antenatal checklist Provide vigilant, flexible support & monitoring of physical & mental well-being Following dating scan, arrange detailed ultrasound in line with NHS Fetal Anomaly Screening Programme standards between 18-22 weeks (RCOG 2016). Additional scan may be requested if valproate/more than one epilepsy medication is prescribed. Growth scans may be required depending on epilepsy medication. Inform Consultant Obstetrician if woman is admitted to hospital. Avoid hospital admission to a single room unattended; consider family member staying overnight. Provide immediate telephone contact/follow-up if any appointments are missed in case of a deteriorating medical condit | de the following: | |
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Complete: first antenatal appointment

If known, age of diagnosis: Who diagnosed epilepsy?

Which hospital?

Name of previous epilepsy medicines prescribed:

Do you smoke: Yes/No How many daily? What is your BMI?

Any previous babies exposed to epilepsy medicine: Yes/No/N/A Medicine name(s):

Congenital malformations: Yes/No **Delay reaching milestones?** Yes/No

Obstetrician/physician & Epilepsy Specialist to complete:

- Complete pregnancy/birth management plan: page 8
- Emergency medicines management of seizure recommended: Yes/No If yes, provide Epilepsy Action buccal midazolam care plan template and administration advice
- Provide information: breast feeding and contraception with epilepsy medicine regime
- Therapeutic drug monitoring recommended: Yes/No
- Valproate prescribed: complete Annual risk acknowledgement form
- SUDEP risk: complete SUDEP Action: SUDEP and safety checklist

Epilepsy medication serum levels are not routinely tested. However, the epilepsy specialist may recommend therapeutic epilepsy medication monitoring in addition to clinical monitoring, especially if there is adherence uncertainty or lamotrigine or levetiracetam are prescribed. Note falling epilepsy medication serum levels in pregnancy may impact on seizure control.

Preconception level: Yes/No Date reported: Serum level:

Pregnancy results

| Medication | Date | Serum level | Range | Signature |
|------------|------|-------------|-------|-----------|
| | | | | |
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Epilepsy medicine changes during pregnancy

| Date | Medication | Recommended change | Signature |
|------|------------|--------------------|-----------|
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Epilepsy medicine post-natal plan: complete antenatally

| Medication | Recommended change | Signature |
|------------|--------------------|-----------|
| | Necommended change | Signature |
| | | |
| | | |
| | | |
| | | |

| | ti-disciplinary team: discuss antenatally & following birth natal advice checklist | Date/signature |
|-----------------|--|----------------|
| 2. | Obtain informed consent to administer vitamin K (1 mg) 1/M for baby following delivery if taking epilepsy medication. Babies exposed to epilepsy medication-recommend expert paediatric examination post delivery. | |
| 3. | Advise breast feeding mothers who take epilepsy medication to alert health professional urgently if baby develops difficulty in feeding, jaundice, a rash or becomes increasingly drowsy. Advise women complete <u>Epilepsy Society risk assessment</u> to optimise safety whilst | |
| 4. | in hospital care. Advise showers rather than baths. Provide information about reducing risks when caring for children from: Epilepsy Action: caring for a baby & young children | |
| 5. 6. | Refer to epilepsy medication post-natal plan (page 4) for medication advice. Encourage woman to alert GP promptly if any changes to medication are made. Advise contacting epilepsy specialist if additional medication support is required. Remind women to take epilepsy medication at prescribed times | |
| 7. 8. | Where possible, provide post-natal home visits to reduce impact of tiredness on seizure control. There should be vigilant monitoring of physical & mental wellbeing. When considering discharging a woman from midwifery care, ensure woman knows who to contact in an emergency if there is any deterioration in her seizure control or mental well-being. Where possible, advise women not to sleep alone due to risk of nocturnal seizures | |
| 9. | Provide contraception advice before discharge from maternity care. Refer to BNF for individual drug advice on interactions with epilepsy medication & hormonal contraception. FPA: long acting reversible contraception FPA drug interactions | |
| | National guidelines recommend GP prescribes folic acid 5 milligrams once daily if risk of pregnancy/at least 3 months before future planned pregnancy for women taking most epilepsy medication. This is usually continued until 12 weeks gestation. | |
| 11. | Ensure women receive the opportunity of flexible support for their epilepsy in the year following birth and before future pregnancies. | |

Arrange urgent postnatal review by neurologist/epilepsy specialist if:

- There is diagnostic uncertainty or when urgent treatment review is recommended
- Seizures increased or were uncontrolled during pregnancy
- There is a history of prolonged seizures or status epilepticus
- Baby was born with a major congenital malformation
- The woman is taking sodium valproate
- The woman stopped epilepsy medication during pregnancy

How can you provide optimal care?

Please refer to your local and <u>RCOG green-top guidelines</u>, <u>epilepsy in pregnancy</u>. If your PCT or local hospital has an epilepsy specialist nurse, make urgent contact with them if further support is required. Encourage women to become experts in their own condition by obtaining further information from: <u>Epilepsy Action</u>, <u>Epilepsy Society</u>, <u>Women with epilepsy</u>, <u>SUDEP Action</u> and <u>Epilepsy Society</u>.

Reference: Morley K (2021) Maternity epilepsy shared care toolkit (PDF). Available from: www.womenwithepilepsy.co.uk

This peer reviewed toolkit was designed to support recommendations from: NICE, Epilepsies: diagnosis & management, 2012; Diagnosis & management of epilepsy in adults –SIGN (2015); RCOG, green-top guidelines, Epilepsy in pregnancy (2016); MBRACE-UK and the National Maternity Review, Better Births, Improving outcomes of maternity services in England (2016). The toolkit was updated in 2021 to reflect findings from: MBRRACE-UK (2020) Saving Lives, Improving Mothers' Care - Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2016–18 and Anti-epileptic drugs: review of safety of use in pregnancy (2021) MHRA. To assess effectiveness of the toolkit's use in clinical practice, research study published in 2020. For further information and support, contact: kim.morley@nhs.net

Pregnancy seizure diary: woman with epilepsy or witness of seizure to complete

| Date & time | Seizure description | Symptoms before seizure (aura) | Symptoms following seizure | Missed medication or other trigger? |
|-------------|---------------------|--------------------------------|----------------------------|---|
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Checklist to discuss in pregnancy to help you prepare for birth

Discuss your birth choices with your midwife and have the knowledge that you can adjust to meet your individual needs. Consider what you do/don't want and feel you can use this check list to help you write your birth choices to maximize your safety whilst in hospital care.

| Example: |
|--|
| ☐ Complete your own risk assessment in preparation of your hospital admission |
| ☐ Order and pack an extra supply of your epilepsy medicines in anticipation of admission to hospital |
| ☐ Set reminders for medication times on your mobile |
| \square Share your birth choices and this toolkit with the hospital midwife |
| ☐ Identifying emergency call buzzers in all hospital rooms |
| \square If your partner needs to leave the room, ask for a midwife to attend to maximize your safety |
| ☐ Continue your epilepsy medicines as prescribed, even during labour; do not miss dose(s) as this could result |
| in an increased risk of seizures occurring |
| \square If you feel nauseous, ask for an anti-sickness injection to prevent vomiting/allow absorption of epilepsy |
| medicines. |
| ☐ Bring a recording of your favourite music that helps you to relax. |
| \square You may find it useful to use relaxation techniques which you practiced antenatally, such as Mindfulness. |
| ☐ Stay as mobile as possible and drink enough water in order you are not thirsty. |
| \square Feel supported and listened to and be central to shared decision making about your care. |
| ☐ Most women with epilepsy are discouraged from using a birthing pool. Ask yourself, would you feel safe if |
| you were to immerse in water during labour; is there a hoist if you needed to get out quickly? Is it possible for |
| someone to be with you at all times? Is this safe if you were to have a seizure? |
| \square If you were supported to have a pool labour/delivery stay well hydrated, as it becomes hot in the birth pool |
| room. If you feel at risk of a seizure, inform your birth partner & midwife and be helped out of the pool, safely. |
| \square Inform your birth partner and midwife urgently if you feel at risk of seizure at any time in the labour. |
| ☐ Avoid pethidine as this is converted to norpethidine which evidence suggests has the potential of lowering |
| seizure threshold. Guidelines suggest that Diamorphine is an alternative analgesia if requiring sleep in early |
| labour; this will change your perception of the pain rather than take it away. Please note this can cause |
| excessive drowsiness and vomiting. |
| \square Gas and air (entonox) is considered safe for most women with epilepsy. Be careful not to over-breath as |
| this can make you feel dizzy, light-headed, with tingling in your lips, hands and sometimes feet. Following the |
| contraction, if you have these symptoms, tell the midwives and they will be able to show you how to relieve |
| these symptoms. |
| \square If you have a history of absence seizures, avoid hyperventilating (over-breathing) if using entonox (gas and |
| air) and when baby's head is delivering. |
| \square Consider epidural if this is your requested form of pain relief or if you require more effective analgesia (pain |
| relief) to allow you to rest. Ordinarily, an epidural is sited when a woman is in established labour. Be guided |
| when to have it by how you are feeling, your level of tiredness, your progress in labour and the expert opinion |
| of the midwives/obstetricians who are caring for you. |
| ☐ Ensure your team have completed the postnatal medication management plan (page 4) in this maternity |
| epilepsy toolkit and reassured you about the safety of breast feeding before you go into labour, if this is your |
| chosen method of infant feeding. |
| |

Pregnancy management and agreed birth plan:

Multi-professional team to complete with woman and file at front of maternity notes

| | Signature | |
|-----------------|-----------|--|
| Situation | | |
| Background | | |
| Assessment | | |
| Recommendations | | |